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ABSTRACT

This manual is intended to assist in the establishment, facilitation, leadership, and evaluation of support programs for fathers of children with disabilities. The manual begins with a foreword written by a father of a child with severe disabilities and a preface by the project director of the National Fathers' Network. An introductory chapter identifies common themes of fathers' programs (e.g., safety, camaraderie, and understanding); benefits of fathers' programs (e.g., discuss and practice the skills of caregiving); and suggestions for using the manual. The second chapter discusses patterns of family life, the father's role/reactions, and results of fathers' support programs (e.g., increased acceptance of the child). The third chapter addresses steps in starting such a group, including obtaining organizational sponsorship, recruiting fathers, determining costs, creative fund raising options, planning for child care, and locating meeting space. Principles of facilitation and leadership based on various leadership models (combinations of a professional and/or fathers facilitating the group) are covered next. Organizational activities (father/child activities, open discussion, educational opportunities, and social activities) are considered in the fifth chapter. Principles of individual and program evaluation are summarized, and the final chapter offers additional suggestions for supporting male involvement. Fifteen appendices provide sample publicity releases and forms, suggested activities, and evaluation guidelines. (Contains 21 references.) (DB)

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Support Programs for Fathers of Children with Special Needs

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James May
National Fathers' Network
The Merrywood School

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Circles of Care and Understanding: Support Programs for Fathers of Children with Special Needs

James May, M.A., M.Ed.

Managing Editor:
Mary McGonigel

First Edition, First Printing
June, 1992

ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH
BETHESDA, MD

DEDICATION

This monograph is dedicated to the thousands of men who have been members of fathers' programs in the United States and Canada. Your concern and sensitivity is appreciated and valued. Through the love and dedication you bring to your families and the other men in your groups, you have brought about a new definition of fatherhood: tough *and* tender, assertive *and* gentle, outspoken *and* compassionate. You have allowed me to become a part of your lives; for that I am thankful.

In Loving Memory of Sarah Beth Blair

June 13, 1984 - December 24, 1990

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- Steven Skeels
- Gary Sweet
- Ray Wilaford

— James May —

FOREWORD

It has been nearly six years since I first became involved with the Fathers' Program at Merrywood School. I attend the meetings because they make me feel good about myself as a father and a husband. I am blessed with three beautiful daughters, and Sarah is my oldest. Sarah has a rare disorder called hypomelanosis of Ito. What little research there is about this disorder has shown that the range of mental disabilities it creates goes from mild to profound retardation.

All the parents I know have said that their children have changed their lives to some degree. But those of us who are raising a child with special needs know that this change is much more dramatic and long lasting. The issues involved in raising a special child are bountiful. Dealing with the medical, educational, and social systems is only the beginning. The tasks, at times, seem overwhelming and impossible to achieve. But yet, we as parents go on. The Fathers' Group has helped me go on.

I became involved with the support group when my wife said it was time for me to get some help. I was irritated, depressed, angry, and any other adjective you can think of when you battle with grief. Trying to deal with the reality of my daughter's disability was too much for me. I remember the first meeting I attended. I believe I said just a few words about myself and Sarah and mainly listened to the other fathers. I was amazed that many of the things they shared with the group were issues I was dealing with. It was as if someone had called my wife and asked what were the problems I was struggling with. From that first meeting I knew this was what I needed.

Many men do not believe or want to believe that they can receive help from a support group — outsiders. At first, I was one of those men. I couldn't understand how sitting around and discussing my disabled child was going to help me be a better father and husband. And to top it all off, I would be discussing everything with a bunch of strangers. I soon found out that the fathers' group did more than just sit around and talk. We share and support each other to help us better understand our children and ourselves as dads. Our support group helped me accept Sarah for who she is as a person; not for what she happened to have. The group has changed me by quietly forcing me to deal with issues I've denied about my daughter. For me, it has been a long journey. After six years I have finally found peace in my heart and total acceptance of Sarah. The group has helped me achieve this and for that I will always be grateful.

Having been involved in the fathers' group since 1986, I thought things were sailing along as well as could be expected. Sure, there were ups and downs, but the downs didn't seem to be as long or as often as before. Part of the credit for this change in my outlook comes from the support and love — yes,

love, I have received from the fathers' group. My faith in the importance and power of this group was made most obvious when Sarah died Christmas Eve, 1990. Eighteen months have passed, but the memories about events surrounding her death are as fresh in my mind as if it happened yesterday. I spoke of the love that I feel I've received from the fathers' group; the fellows who came to Sarah's wake and funeral; those who sent cards and called; the kind word, the embrace, the hand on the shoulder. These are the memories I will always cherish and think about; this is what I mean about support. And those wonderful gestures haven't stopped because time has gone on. Dads still ask how things are going — and they sincerely want to know; they're not just trying to create idle small talk.

Words cannot adequately express how the fathers' support group has helped me and my family. Perhaps actions can. Even though Sarah has died, I continue my involvement with the dads' group. There is still much for me to understand, and I believe I have much to share with the other men. The dads in our support group have a common bond — our children. That is something we will always have.

I hope reading this monograph will motivate you as well as give you the tools to organize a fathers's program in your area, whether that be through a hospital, school, early intervention agency, church, or parent organization. The experiences I have shared with you regarding the value of a fathers' program will undoubtedly be replicated by other men. The families, and the children who live in those families, will indeed be well served. We owe them, and ourselves, nothing less.

Paul Blair
Woodinville, Washington

Photo: Gary Sweet

Paul Blair with his daughter, Sarah

PREFACE

I welcome the chance to share ideas with you about establishing fathers' support programs. Having helped to develop and facilitate such programs for almost six years, I have seen firsthand the power, the involvement, and most importantly, the healing and transformation that can come about from such groups. Simply stated, men need places to talk with other men about their common concerns and shared feelings. A fathers' group is such a place; it cuts through isolation and fear and replaces it with acceptance and confidence.

Wherever I have spoken or presented workshops, there is almost universal agreement that fathers — indeed, all men — should be more fully involved in the care of children. This is particularly critical when those children have special needs. Yet professionals and family members alike are often unsure about how to bring about such enhanced involvement.

Increased involvement begins with an examination of the attitudes and beliefs parents and professionals have towards men and how they engage in their children's lives. Formidable mythology exists about males as "derelict dads" and absentee fathers, irresponsible in carrying out their fatherly responsibilities. The media has often contributed to these stereotypes by portraying fathers as stupid, insensitive and unaware, or just plain macho, beer-drinking buffoons. While some men do have limited perceptions of their roles in their children's lives, these roles gain new meaning when a child is chronically ill or disabled. The thousands of men I have met in my work with fathers' programs demonstrate that such stereotypical images are inadequate, unhelpful, and simply untrue.

Family-centered care recognizes "that the family is the constant in a child's life" (Shelton, Jeppson, & Johnson, 1987, p. 3). Family is mother and father, brothers and sisters, grandparents, aunts, uncles, cousins, neighbors, church members — all those who are significant participants in a child's life. What better means for supporting and enhancing family stability than through the establishment of programs for fathers whose

children have special needs. A Vermont dad, Peter Schumer, articulates this thought eloquently when he comments that the men help him:

> make it through another month with my emotional and family structure intact. Meeting with others who know how I feel alleviates my sense of loneliness and isolation . . . Though the specifics of our children's disabilities vary, we all share a commitment to be honest and open about our individual situations. In so doing, we learn from each other's mistakes and experiences. Painful and embarrassing experiences can be put in a more humorous light once we realize others have faced similar obstacles. I am indeed fortunate to be surrounded by such a group of thoughtful and caring people.

This monograph will help you provide new and creative avenues for supporting fathers and the children and families they care so very much about. I have delighted in the moments spent with such men; their strength, honesty and compassion have taught me much about parenting, and even more about myself. Their stories will help you catch the vision of what a fathers' program is about. I look forward to hearing your success stories.

James May
Project Director
National Fathers' Network
The Merrywood School

Chapter 1

Introduction

It's Just That We Have So Much In Common

The men were casually talking about their children, bouncing from topic to topic with no apparent transitions. Finally the discussion settled on the issue of advocating for one's child with special needs in the schools. The atmosphere intensified and voices became increasingly concerned, even strident. "I thought the teachers were there to support us, not hold us back." "It's as if we have to fight for every little gain. If my wife and I don't always push hard, who else will?" Knowing nods appeared around the circle. Finally, a metaphor burst forth from a man who had said little up to this point: "It's like hitting a brick wall; no matter how often you pound on it, it just won't give in." The discussion continued another twenty minutes or so, and finally the father in charge suggested there be a break. A dad attending for the first time asked aloud, "You guys must know each other really well to talk this openly." "Not really," one man said, "it's just that we have so much in common."

Such a comment speaks volumes for why there are increasing numbers of groups for fathers of children with special needs. Yet, one must ask, are fathers' needs so different that they require special programs for men only? Why not have such support programs for couples? What makes a program for men unique? The answers to such queries are complex and diverse. The many men who shared personal stories and ideas for this monograph provide compelling answers to these questions.

Same Language, No Explanations Necessary

Jeff Raefield, a five-year fathers' group participant, remarks:

> The fathers' program provides me with a place to go where I can be emotional, or not; optimistic, or not; happy, or not; angry, or not. In short, a place where I can feel what I need to feel, without fear of the effects on my loved ones. It is a place to share my burdens with others who, at some time or another, have had similar experiences. It is a safe haven from the subtle pressures on men to show that 'everything is fine.'

Steve Fatica observes:

> I started attending the support program and its special functions because I thought there might be value for me and my family in being exposed to other families with special needs members. There was tremendous value in that exposure, but I also found more, especially in the dads-only meetings. What I found was that some of the thoughts and feelings I was having weren't unique to me. These feelings were shared by many others in situations similar to mine. That knowledge has been a great source of strength and comfort. Now I'm trying to learn to better understand those feelings and to share them in an open and honest way. In the almost two years I've been participating in the program I've heard from one dad who has gone through a divorce, one who tragically lost his special needs daughter in a freak accident, and another whose wife recently gave birth to their second child with spina bifida. Watching these men try to cope has taught me a lot. I also like to think that maybe I was some help to those men because I was there for them when they needed someone.

Photo : Gary Sweet

The Merrywood Fathers' Network

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Chris King describes how a fathers' program creates not only a relaxed atmosphere, but also an arena to be recharged and refocused:

> I like having a place to go where people really understand what it is like to have a kid with special needs. Most of my friends who lead 'normal' lives, if there is such a thing, are truly concerned about what's going on with Andrew and the rest of my family. But, it is difficult to discuss the circumstances of our daily ups and downs with those who have not walked the walk. The atmosphere at the fathers' meetings is very relaxed and informal. That feels especially good to me. I like the opportunity to kick back for a few hours without kids and other family demands in my face. After the meetings I feel like I am probably a better father and a little easier to live with for the rest of the weekend.

To Gary Sweet the real value of a fathers' support program is the "companionship with the guys." Doug Mitchell talks about how it is "nice to be with fathers — same language, no explanations necessary."

Common Themes of Fathers' Programs

Common themes emerge in these responses that clarify the *why* of a fathers' group. The men attend for:

- ***Safety*** — a place to let down one's guard, to be taken seriously, to know that what is said will be held in strictest confidence.
- ***Exposure*** — to new information, to shared feelings, to firsthand experiences.
- ***Relaxation*** — a place to unwind, to laugh, to swap stories rarely told and often misunderstood by others who are not raising a child with similar concerns.
- ***Camaraderie*** — a place to make new friends, friends to reach out to, to share with, and yes, to lean on. "It's kind of like an old friend who you don't see for a long time, but when you get together it's like you have not really been apart. Maybe it is because we are all having our struggles of one kind or another."
- ***Understanding*** — of how to manage the powerful feelings of anger and joy, hate and love, control and chaos that all parents experience when confronted with a child who has extraordinary needs.

A fathers' program empowers. Such empowerment allows men to tell the truth and not be judged adversely because they do. Discussion is done in circles of care and understanding. It is a time to explore, to question and probe, and ultimately to be understood. There is learning about oneself — one's values, grief, hopes and joys — and about how men ultimately redefine themselves and their fatherhood in relationship to their children with special needs and their families.

Lessons From a Fathers' Program

From both personal growth and child development perspectives, a fathers' program provides avenues for men to:

- ❑ ***Discuss and practice the skills of caregiving*** in a non-judgmental atmosphere of acceptance.
- ❑ ***Learn how to read children's communication cues,*** interpret behaviors, and improve overall patterns of parent/child communication.

Photo : Gary Sweet

Ray Willaford with his son, Patrick

- ❑ ***Learn about playing,*** interacting with, and disciplining children in developmentally appropriate ways.
- ❑ ***Gain information*** about their children's special needs and the resources available to help their families.
- ❑ ***Discuss and share personal concerns*** with other men.
- ❑ Gain increased understanding about ***personal grief and loss.***
- ❑ ***Provide respite*** for mothers, brothers and sisters, and extended family members.

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In sum, a fathers' group gives men a place to learn, to open up, to laugh, and to cry. Chris King captures this thought:

> Bottom line, I like the group. I like the interaction with other men who do become exceptional people in the sense that they have been humbled by their circumstances. Yet, they rise above them out of love for their families and the determination to make things as normal as they can be for everyone involved.

Key Areas For Discussion

This text serves as a companion piece to the monograph *Fathers of Children with Special Needs: New Horizons.* Together, they make an important statement about men as caretakers, nurturers, and essential figures in the lives of their children and families. This second monograph focuses on the following areas:

- ❑ A brief overview of research
- ❑ Starting a fathers' program
- ❑ Leadership and facilitation skills
- ❑ Models of organization
- ❑ Results and evaluation
- ❑ Appendices, including sample forms and other resources

How to Use this Monograph

It is strongly recommended that users of this monograph read the work from beginning to end. Each chapter is designed to build upon the ideas presented in previous chapters. The appendices contain resources in areas essential for group success. Turn to each appendix when it is mentioned in the text; doing so will add considerably to your understanding and grasp of this material. Many of the appendices are ready to be copied for group usage.

The ideas and suggestions contained herein should help staff in any organization or agency start an effective program for fathers. The outcomes for the men involved can be profound. Paul Malinowski describes his experiences in a fathers' support program as:

> . . . simply some of the best I've ever had. I've learned not to be so hard on myself when things don't go normally in my child's development. I have learned that feeling sorry for one's self is perfectly natural and okay if not lingered on. But most of all, I've learned that there is hope for me and my child as I hear success story after success story from other fathers, particularly those with older children. Fear of the unknown for my child's future weighs heavily on me, but hearing from others how problems can be mitigated throughout a child's life constantly refreshes my outlook for the future.

All the quotations used throughout this monograph are from fathers of children with special needs. The fathers quoted include men from a broad spectrum of racial, ethnic, geographic, and socioeconomic backgrounds. Their words are powerful reflections of the thoughts and feelings of the many men who are special dads to their children.

Photo : James May

Steven Skeels with his son, Taylor

Chapter 2

Background

Every individual who comes to the group arrives carrying a load of stress, concern, frustration, joy, and questions. Each is involved in a different vocation as well as family setting. I have seen the 'oneness' that develops in a few minutes of sharing some tough life situations with one another. There is the sense that we all understand one another in a way no one else can who is not involved with the ongoing care of a person with special needs. [Jim Lamb]

The Family Mobile

Family members cannot be talked about in isolation. They are interconnected and interdependent. This family ecosystem can be likened to a mobile, in that all people live together in a delicate balance. What happens to one person directly affects all other family members.

While families are generally quite resilient and able to cope with stresses and shocks to family equilibrium, some events occur that overwhelm this balance and threaten to collapse the existing family mobile. Chronic health conditions and disabilities can be such events. The family mobile may never be the same, and family members will endeavor to regain stability in the face of increased stress and anxiety. The ability of a father to positively handle such major changes can greatly enhance household well-being. Conversely, his inability to cope with change negatively undermines the responses of the entire family.

When typical patterns of family life are disrupted through a child's special development and health concerns, parental roles often become tightly defined. Traditionally, the mother almost always will be the primary caretaker — the designated expert — involved in the daily concerns of the child's medical treatment, intervention services, and care at home. The father generally will maintain his primary role as financial provider; in

that role there is both strength and strain. Often a man has learned "that the economic security of his family is his most sacred, possibly only, legitimate domain. Men learn early that the 'correct' way to father is indirectly." (Pruett, 1987, p. 18).

Few men have examples of male parenting that include caretaking and nurturing, particularly caring for a child with special needs. Dominant male models, part of the Western culture, reflect a man's desire to be in control — to be competitive, protective, a problem-solver. Many men value self-sufficiency and do not openly share feelings with peers.

Photo : James May

David Isett with his daughter, Annie

When a child has a chronic illness or disability, these views of fatherhood are often inadequate. No quick fix is available. A father's hopes, dreams, and ideals for his child, particularly for a son, are devastated, and his self-esteem may be threatened (Farber & Ryckman, 1965; Pruett, 1987; Tallman, 1965). He knows he didn't protect his family from the disability, and he fears many of the decisions the family must make are out of his authority. He may have difficulty getting in touch with the feelings swirling inside him, and his self-sufficiency often makes asking for help a formidable task. He must reconcile conflicting conceptions of his role as a father and discover means for redefining himself as a man (Duvall, 1962). In the words of one father, "It's as if the whole world crumbled before my feet, and I wondered where I would begin." New values are slow to emerge.

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Fathers of children with special needs often feel isolated. As Jim Lamb says:

> In the beginning, I was not at all interested in being involved in any group of people sitting around talking about their troubles with special needs family members. I had the feeling that hearing about other individual's difficulties would only be counterproductive. I felt I had enough problems of my own without surrounding myself and my family with others who have similar frustrations and stress.

Many men have difficulty accepting the truth about their child's condition, not only in the severity of the challenges, but also in the physical and emotional manifestations. Fathers are often embarrassed and sensitive about a child's delays and physical appearance, and about how the child affects family social status and image (Price-Bonham & Addison, 1978). They want information on ways to discuss their child with relatives, co-workers, and strangers who may stare, compare, and make inappropriate remarks.

Many fathers perceive that social supports from family, co-workers, neighbors, and community groups are often limited: "My kid doesn't do what other kids do; why and with whom would I discuss that at work?" This lack of support compounds a man's isolation (Ferrari, 1986). Believing they must be "strong" at all costs, men often limit their potential for expressing concerns and fears and for finding strength through sharing. Too often work becomes an escape and a means for dulling the pain. Because most health, education, and social services are provided during the day, a father's work schedule will likely limit his firsthand knowledge about his child's special needs, thus creating a continuous information gap between mother and father.

Fathers traditionally relish playing with their children as well as taking them on outings; both roles may be seriously disrupted when children have special needs (Gallagher, Cross, & Scharfman, 1981). Fathers often need help learning to read their children's communication cues: "My kid never made eye contact with me; he didn't smile much, and he always cried when I tossed him up in the air." Learning about appropriate father/child interactions; acquiring sophistication in discipline, feeding, and using adaptive devices; and gaining advocacy skills become paramount.

There is increasing evidence that fathers set the tone for a family's attitude towards a child with special needs (Frey, Fewell, & Vadasy, 1989; Peck & Stephens, 1960; Price-Bonham & Addison, 1978). It is therefore imperative that high quality personal, educational, and medical supports be developed for fathers. They need to recover personal control through coming to terms with their grief, gaining emotional support, and becoming active participants in the decisions affecting their children's lives. To do so will open lines of communication for all family members and accelerate the healthy rebalancing of the family mobile.

Results of Fathers Support Programs

Researchers have consistently concluded that there should be increased supports for fathers of children with special needs (May, 1990). A fathers support program has proven to be a powerful vehicle in reaching men who might otherwise become or remain detached and separated from their families. Research studies (Markowitz, 1984; Vadasy, Meyer, Fewell, & Greenberg, 1985) conclude that fathers support programs can:

- ❑ Improve family communication
- ❑ Improve self-esteem, reduce feelings of failure
- ❑ Reduce stress, tension, depression, and fatigue
- ❑ Increase sharing of chores and responsibilities
- ❑ Enhance family support systems
- ❑ Increase acceptance of the child
- ❑ Enhance consistent discipline of the child
- ❑ Increase family harmony

The research indicates that the above changes occur for both fathers and mothers. Recent research provides evidence that these changes endure over time, even when a father is no longer a member of a support group (Frey, Fewell, Vadasy, 1989; Frey, Greenberg, & Fewell, 1989).

Fathers' programs provide avenues for men to connect and bond with their children and with each other in the most loving manner possible. David Novak, a father in Iowa, speaks for all fathers when he says, "Our children need us and we need them."

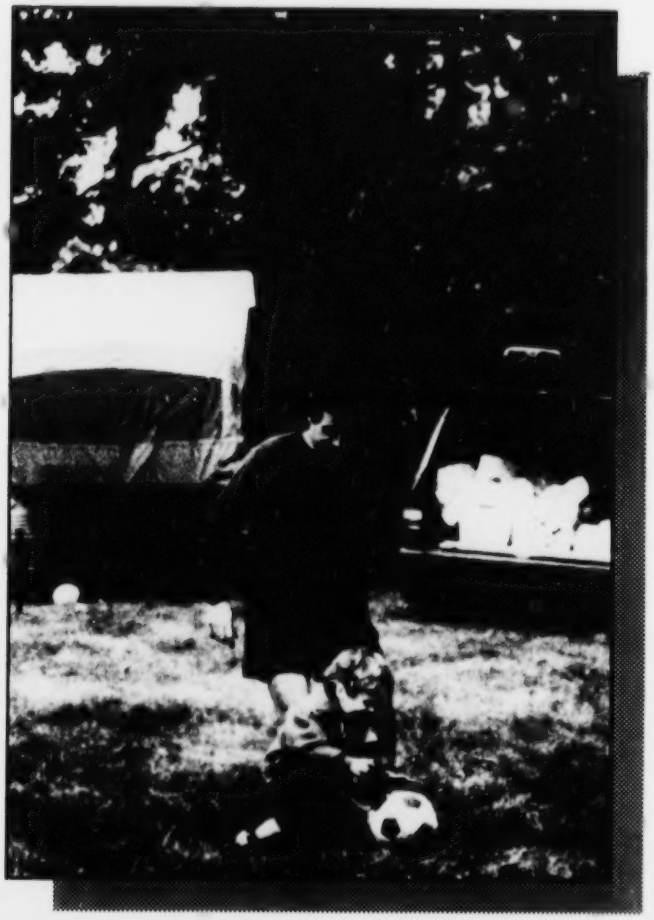

Photo: Gary Sweet

John Doherty with his son, Charlie

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Chapter 3

Getting Started

A particular incident stands out in my mind from my involvement in the program. The first couple of meetings I attended, I noticed another father who also was attending his initial meetings. He sat in the back of the room each time and never said anything. He disappeared and I forgot about him until he reappeared eight months later at our last meeting of the year. Again he sat in the back of the room and said nothing. I found it odd that he would come to the last meeting of the year just to sit and say nothing. Finally, towards the end of the meeting, the group leader gave him an opportunity to use some time if he wished. At first he was very reluctant, but then it became obvious he was there to talk through that reluctance. For the next 45 minutes or so he recounted how his child had become disabled, how that had affected his life and his marriage, and how he felt about his situation — and to our astonishment — about how he had never told anyone the things he told us that morning. It was one of the most emotional experiences I've ever had in my life. [Paul Malinowski]

How does any agency, hospital, or school start a father support program? What are the hallmarks of success? What ensures fathers wanting to attend? Must such programs be costly to develop and maintain? These are often-asked questions; many of the answers will be determined by the fathers themselves and the specific concerns they express.

Sponsorship

Most fathers' programs are sponsored by organizations such as hospitals, schools, early intervention agencies, University Affiliated Programs, ARCs (Advocates, Resources, and Counseling for persons with developmental disabilities), or parent-directed advocacy groups. Typically, two or more organizations will work together as a sponsoring consortium, thus reducing

costs and developing a broad base for recruiting men. The roles of the sponsoring agency include:

- ❑ Providing space for meetings
- ❑ Helping to develop a quality child care program (if needed)
- ❑ Providing financial assistance
- ❑ Actively assisting in the recruitment of group members through staff support, advertising, or media contacts
- ❑ Developing leadership
- ❑ Integrating the concerns of fathers and the fathers' support activities into the agency's program model and the delivery of family/child services

Agency personnel must embrace a fathers' support program as important and necessary to the agency's framework of family services, rather than consider such a program as an add-on or as the agency's only connection with fathers. It should be developed as one component of well integrated, family-centered services. Fathers should always be encouraged to participate in classroom and therapy sessions, the individualized family service plan (IFSP) and individualized education plan (IEP) meetings, as well as serve on local, county, and state boards for creation of family policy.

Recruiting Fathers

There are many ways to attract fathers to a support program. Among the most successful are:

- ❑ ***Media publicity, including newspapers, television and radio.*** Because of the uniqueness of fathers' support, the media is generally open and receptive to publishing public service announcements, articles, and interviews. Unfortunately, while media exposure often increases public awareness of children with special needs, it generally does not recruit large numbers of men. (See Appendices A and B for an example of an article printed about a father support program in the Puget Sound area and a sample press release.)

- ***Agency referrals of fathers to the program during intake or regular service delivery.*** This approach is both indispensable and highly successful. The message is clear and immediate: having a child with special needs demands full family involvement. Fathers are important and not to be forgotten. Agency staff should be provided with printed material such as an overview of the program and a schedule. (See Appendices C and D.) Staff should also have firsthand, accurate, working knowledge of what the program is about, who to contact for more information, transportation, etc.

- ***Contacts with early intervention centers, schools, hospitals, and parent advocacy groups.*** Having a broad network of referral sources means fathers do not get lost between the cracks and guarantees a continual infusion of new men into the program, so vital to a group's success. Program information should be sent to a specific person in each agency (by name and title), and a follow-up call should be made.

- ***Invitations by current fathers to potential group members.*** A physician or an early intervention program staff member, for example, may ask a father or mother if another father of a child with special needs (current group member) may call him to discuss the program. If a parent is willing to be called, he or she should be contacted by a father whose age, background and child's disability most clearly match the potential recruit. *Individual recruitment is, far and away, the most successful means for bringing new dads into the program.* The contact lets a man know he is not alone in his concerns, gives him information about how the program works and who attends, and most importantly, introduces him to a contact who can provide support and assistance when he first joins the group.

- ***Fathers contacting other fathers once the program is underway.*** Most men know other dads whose children have similar concerns; these other dads often respond positively when approached by a father who knows firsthand what they are experiencing.

- ***Informational talks about the program.*** Ideally, these talks should include fathers already in the program speaking to the *why* of the program and *what* the program is about. These talks can be given to professional staff, parent organizations, church groups — any place fathers of children with special needs attend. Conferences where fathers speak out also attract professionals willing to make referrals.

Men need to know that programs for fathers do exist. Too often a man will not join a program until his child is already six or seven, and he will later remark, "How come I never heard about this program before? I would have joined years ago." Appropriate, father-centered recruitment can avoid this delay.

Once fathers have been recruited, it is helpful to keep them linked to the fathers' program by building a group roster and sending information about each meeting a week to ten days in advance. (See Appendix E for two samples.) This letter provides a connection between sessions (each letter quickly summarizes what transpired at the last get-together), and serves to promote and market upcoming programs. It keeps the program foremost in the men's minds. The tone of the letters should be light, upbeat, and humorous.

Photo: Gary Sweet

Dominador Monillas with his son, Dominic

Cost

The cost of a fathers' program depends upon many factors. Does the program rely on volunteers or paid personnel? (Volunteers are particularly important for child care.) Are guest speakers paid honoraria? Are the men asked to pay a yearly fee for attending the program? Do the dads offset the costs of child care by paying for each session? Does a yearly fund raiser help defray costs? These and other questions must be answered; they are fundamental to how the program is organized and structured.

Areas in which costs might occur include: leadership and facilitation, particularly if the leaders are not staff members of the sponsoring agency; honoraria to guest speakers; postage, printing and clerical assistance; child care; snacks and drinks; special events (seminars, potlucks, barbecues, picnics, outings); rental of facility and accompanying utilities; and transportation.

Creative Fund Raising Options

The above questions also speak to how inclusive the program is. Of crucial importance is to make the program accessible to *all* fathers of children with special needs. A father should *never* be excluded from attending the program for monetary reasons. Thus, most programs find creative, resourceful means for financing the program, including:

- ***Voluntary donations from the fathers able and willing to pay.*** The amount given is purely a personal matter. If the sponsoring agency is a non-profit organization, some of the men will be able to match their donations through their work place.
- ***Yearly fund raisers***. Pancake breakfasts, rummage sales, pledge drives in conjunction with a walkathon, sporting events, raffles, etc. have proven successful with many groups.
- ***Small grants available through local, regional, and state organizations.*** Such groups as Kiwanis and Rotary have been particularly receptive to such grants. Grant amounts given generally range from $500 to $1,000.
- ***Financing the program as an agency line-item expense*** — similar to services such as physical, occupational, and speech

therapy. This assures the program's stability as well as reduces the pressure on the men to continually raise money.

According to the needs and size of the program, the cost of developing a father support group may be minimal (a few hundred dollars) or rather sizable (several thousand dollars). The men's shared responsibility for all or part of these costs builds personal ownership in the program; they give because they receive something back.

Child Care

Predicated on the fact that most father support groups meet on Saturday mornings, the majority of programs involve the children of the men who attend. This involvement typically is in the form of father/child activities and child care while the fathers attend the sessions. While it is never mandatory, fathers are encouraged to bring their children, including the nondisabled brothers and sisters. This allows other fathers to gain firsthand knowledge of the children they hear about; gives mothers a break; gives the men a chance to engage in developmentally appropriate play with their children; and gives each man a place to be comfortable with his child.

Child care staff should be knowledgeable about children with special needs. All fathers should fill out a registration sheet with information about the family and child (See Appendix F), including a list of special concerns and medications used. Some programs use agency staff whose time is considered part of their regular contract; others use outside personnel, including young adults well trained in working with children who have special needs.

The child care staff or volunteers should consistently participate so that the children and fathers are comfortable with them. Strive for a four to one child to staff ratio so that staff can create a stimulating environment for the child, rather than just baby sit. Child care staff must know first aid, cardiopulmonary resuscitation (CPR) as well as meet all applicable local and state qualifications. Adeptly managing the child care space promotes cooperation among regular staff; nothing provokes anger more quickly than a room left uncleaned and in disarray. Clear standards for space usage should be clarified and understood by all.

Having an effective child care program and staff is crucial to support group success. Fathers — and their wives — need to know their children are safely taken care of. The more a father can relax about the care of his child, the better he can engage in the group.

Meeting Space

Serious consideration must be given to choosing the meeting space. A number of key factors will influence this decision:

- ❑ Is the meeting place centrally located and easy to find?
- ❑ Is there enough free or inexpensive parking available?
- ❑ Is the space wheelchair and disability accessible?
- ❑ Is there little or no charge for use of the space?

Also important is the atmosphere of the meeting space. Many groups avoid meeting in hospitals and other settings that have a clinical feel, as these settings are often a reminder of the child's continuing or potential problems. One father said that going to the hospital for so many years to help his son was tantamount to "replaying memories difficult to deal with; it is just a place I feel uneasy about." When possible, the space should be open, airy, upbeat, and informal — a place where the men can relax and feel at home. Comfortable chairs, access to a kitchen for a cup of coffee and a doughnut, and restrooms with a changing table in evidence are important and necessary.

Circular seating allows everyone to see and hear each other. This arrangement not only democratizes the group, but also creates an air of informality. Also, late comers can always be welcomed into the group, and space can easily be made available for them. To sit outside of the circle is to be literally outside of the group.

Summary

Starting a fathers' group takes planning, perseverance, and patience. The rewards can be extraordinary. Men discover they are not alone; they allow feelings to surface that were hidden, either from themselves or others, and they gain resources, personal insight, and strength. As defined

by a group member, Chris King, the hallmarks of an effective group include:

Welcoming new guys with open arms.

Remembering not to get so comfortable with seeing the regulars that we forget to be sensitive to the needs of the new guys, who may not yet be able to open up and share.

Keeping a low-key approach so as not to intimidate or scare off anybody.

Continually advising where help can be found in locating services from the state, etc.

Involving the family in many of the group's activities (picnics, holiday parties, etc.).

Just letting somebody know that there is a person he can call if he needs to talk.

As Gary Sweet simply states, "It's a fathers' network; we help each other out."

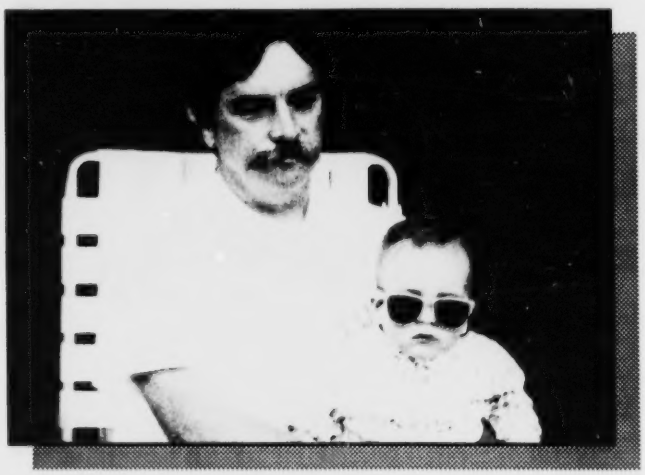

Photo: James May

Gary Sweet with his daughter, Cailin

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Chapter 4

Effective Leadership And Facilitation

We learn, when we respect the dignity of people, that they cannot be denied the right to participate fully in the solution of their own problems.

Self-respect arises only out of people who play an active role in solving their own life crises and who are not helpless, passive, puppet-like recipients of public and private services.

To give people help, while denying them a significant part of the action, contributes nothing to the development of the individual. In the deepest sense, it is not giving but taking — taking their dignity. Denial of the opportunities for participation is denial of human dignity and democracy.

It will not work.

Sol Alinsky
Rules for Radicals

Developing effective group leaders is crucial to a program's ability to flourish. The group leaders' ability to develop a climate of trust, camaraderie and unity, will go a long way in determining a group's overall effectiveness. One father put it succinctly:

> If the leaders set an atmosphere of acceptance, friendliness, and openness themselves, then gradually others will respond accordingly. If men have the feeling they are being heard, and have the opportunity to share, it will be successful. A good leader can direct conversation to include the quiet guys, too. If that happens, all will feel they have contributed as well as benefited. [Jim Lamb]

Leadership Models

It is imperative — and axiomatic — that fathers' programs be led by males. In the words of one father, "Having an all men's group seems to make it much easier to say what is on your mind. It cuts through a lot of b.s. I know I feel free to say things that I most likely would not in front of a group of women." There are at least three options for developing support group leadership. They include:

- ❑ a professional (i.e., counselor, educator) facilitates the group
- ❑ a professional and father co-facilitate the group
- ❑ a father or core of fathers facilitate the group

While each model has its strengths, the common factor among them must be empowering the men and helping them develop a program that speaks to their unique needs and concerns. Given that imperative, each program will then succeed according to the maturity, organizational skills, perseverance, and personal presence of those involved. If the men claim the program as their own, and if they value what happens during their times together, the basis for success is in place.

Effective Father Leadership

The pivotal people in a fathers' group are the fathers themselves; a professional, if used, must acknowledge that principle. Effective father support programs generally have a core of men who provide leadership, participate actively, and are willing to pitch in and do what it takes to make the program successful. From that core, one or two dads should be identified as primary facilitators. Their being fathers of children with special needs is the basis for their credibility. Key qualities for these leaders include:

- ❑ ***An emotional maturity*** — that allows them not only to model appropriate self-disclosure, but also to subordinate their personal needs and feelings to those of the other men. Most leaders have children in the primary grades; they have dealt with their own issues of grief and have gained the necessary distance and insight to be of help to others.

- ***An ability to be well organized*** — to plan and use time well. Writing letters, planning meetings, and making decisions all demand efficiency and consistent follow-through.
- ***Superior listening skills*** — combined with the ability to help the men be comfortable in the group and comfortable with the feelings they are sharing.
- ***A willingness to reach out*** — to recruit new members.
- ***An enthusiasm for the program*** — and for the families involved in it — this is essential.
- ***A sense of humor*** — an ability to laugh, even in the midst of the joys, pains, and absurdities of family life.

Effective Professional Leadership

For those groups using a professional as a co-facilitator, it is best if the professional has a background in child and family development. This person often is a social worker, counselor, psychologist, or special education teacher or therapist. A working experience with families of children with special needs is an additional asset. Critical qualifications for this professional include:

- Respect for and ***working knowledge of the cultures*** that make up the communities of which the fathers are a part.
- Possession of an ***effective resource base*** (materials, speakers) and a willingness to market the program to individuals and agencies in the area.
- An ability to generate a ***solid base of referrals*** (counselors, programs).
- A working ***knowledge of crisis intervention,*** including suicide, domestic violence, and child abuse.
- Demonstrated ***organizational ability*** (recruitment, finances, scheduling).
- An understanding of ***group dynamics*** and group facilitation skills, including familiarity with the principles of active listening.

Beyond these characteristics, crucial qualities for the professional are compassion, sensitivity, and unbridled energy for the fathers, for their children, and for the families they represent. He cannot afford to come across as formal, clinical, or as the "expert." He must be able to stay within the boundaries of his identified roles, be assertive when called for, and be laid back when appropriate. Unless he has a child with special needs, he must always keep in mind that he does not have an everyday understanding such a child brings to one's life. He may empathize, feel much sympathy and compassion, but he will not know firsthand what it is like to live with a child with special needs twenty-four hours a day. This distinction must always be remembered and respected.

Guidelines For Facilitating Father Support Groups

Facilitating family-centered support groups for fathers of children with special needs requires that the leaders do the following:

- ❑ ***Build the group from within.*** Assure the members that this is their group, that it will be structured to fit their needs and concerns. Periodic needs assessments allow the men to clarify these concerns. (See Appendix G for an example.) Needs assessments will also identify which topics to pursue.
- ❑ ***Establish explicit group norms.*** Be clear on the program's purpose, the time and length of meetings, and the expectations members have for the group and for each other. Norms must be acceptable to all participants and should be periodically reviewed. Consider such areas as confidentiality, sharing of group responsibilities, and listening and respecting ideas, particularly those different from one's own.
- ❑ ***Begin each session with a "check in."*** While this is not a rigid rule, most groups have found it useful. A check in involves a brief statement by each group member indicating who he is, what his child's special needs are, and what is going on in his personal and family life. It serves to build group cohesion and is an excellent way to help new members feel accepted. Although some programs find it valuable to conclude by having participants share what they learned or discovered from the session, this can be unwieldy.

Photo: Gary Sweet

The Merrywood Fathers' Network

- ***Focus on feelings.*** Primarily emphasize the men's feelings, and avoid intellectualizing and debating ideas. The group is a place for support. Do not be afraid to encourage discussion of grief, guilt, anger, depression, and sadness. These are the emotions the men have in common; the chance to communicate such feelings in a trusting atmosphere is what makes the program powerful to those in attendance. Note that some men have a difficult time identifying their feelings. (See Appendix H for a worksheet that speaks to this concern.) Helping members be clear and specific about their feelings is an essential role for the facilitator.

- ***Guide the interaction.*** *Facilitate* is "to allow to happen, to make easy." Facilitators serve as gatekeepers, assisting members to speak and then gently closing a subject when the discussion is completed. Beginning groups will be well served by using the topics found in Appendix I, "Fathers Only Session".

- ***Practice active listening.*** Some men tend to speak rather than listen. Encourage group members to clarify, paraphrase, and understand the ideas of others. Urge them to be nonjudgmental in their responses. Modeling and having the men practice active listening skills is a must. (See Appendix J.)

- ***Stay with the speaker.*** When one person is discussing a concern or issue, stay with him until he is finished, rather than allowing other members to take the floor by piggybacking on his thoughts.

- ❑ ***Remain in the present.*** Focus on what is currently going on in the lives of the men in attendance. Avoid long stories involving past history or discussing people who are not at the meeting.
- ❑ ***Develop interventions to limit problem behaviors.*** Avoid letting members monopolize air time, and find ways to limit excessive anger, continual complaining, and blaming. Name-calling of group members is never appropriate. (See Appendix K for strategies to curb the dominator, limit negative emotional outbursts, avoid put downs of others, and head off side conversations. Also included are means for assisting the quiet non-participant.)
- ❑ ***Summarize the Discussion.*** As much as possible, bring ideas together and complete one topic before moving on to another.
- ❑ ***Help the fathers access effective resources.*** Provide means for the men and their families to learn about children with special needs. Whether this be through referral services, books, pamphlets, videos or speakers, find avenues of information about such topics as advocacy; working with service providers; insurance; trusts, wills, and guardianships; supported employment; and respite.
- ❑ ***Share the leadership.*** As members mature and develop increased interpersonal strengths, they need places to practice leadership roles. Encourage these men to speak at local organizations; ask them to contact prospective speakers, or give them specific areas of the program to run (i.e., potlucks, outings, social occasions, letter writing, managing a work day or fund raiser). Encourage them to co-facilitate meetings. Effective leaders reach out to men and give them opportunities to develop their skills. This not only empowers members, it also widens the leadership base.
- ❑ ***Allow for growth.*** All groups progress through recognizable stages of role and trust development. A fathers' group should never be pushed to be something it is not ready to be. (See Appendix L for a model of group growth and development.) Building such trust demands patience and an ability to let the men discover how the group can be of value to them and how they

ultimately will benefit from each other's friendship and knowledge.

- ❑ ***Never define success by the number of men in attendance.*** Enjoy all those who participate, whether it be four or fourteen. Numbers will increase when the men take personal responsibility for the group, when they reach out to others and invite them to attend, and when they believe that the program is so valuable — to their families and to themselves — that it simply must exist.

A Final Awareness

A fathers' program is *not* a therapy group, and it never should be. Certainly there will be some therapeutic moments and some bursts of personal understanding and insight. Primarily, a fathers' group is a place for fun, for relaxation and connection with other men and their children and families. There will be down-home, earthy humor; poignant as well as comical stories; moments of great pride when a father recounts his son's first awkward steps, his daughter's transition to public school, or his family's first ever weekend outing. These are the special moments of fathers' programs. Effective leadership allows these moments to be shared and savored. As Paul Blair remarks, "I always feel better when I leave the fathers' meeting. I feel cleansed."

Chapter 5

Organization

On Fathers' Day, 1987, we were living in Alaska. I picked up the Sunday Seattle Times and read a front page article about The Merrywood School and the Fathers' Program. We had already made the decision to move to the Puget Sound area so that Jacob could get the services he needed; the Fathers' Program was the frosting on the cake. I remember my first meeting; I am not a joiner and was somewhat apprehensive. I shouldn't have been. I was welcomed with open arms. I went home that afternoon with a note pad full of information. There I was, brand new in town, and I already had a list of the best doctors, therapists, and schools. [Gary Sweet]

The vast majority of fathers support programs are composed of some or all of the following elements:

- ❑ father/child activities
- ❑ open discussion
- ❑ educational opportunities
- ❑ social activities

A group develops its programs according to the stated needs of the men involved, their time availability, the financial constraints of the sponsoring agency or agencies, and the ability of the chosen leaders to provide the desired services. Some programs incorporate all four elements; others emphasize one or more areas or concentrate on different elements during each session. Whichever format the group chooses to emphasize, it is critical that all members feel involved in and vital to the program.

Building Inclusion

Feeling involved is set in place the first time a man arrives for a session. A father needs to have his potential anxieties reduced with a warm, "Hello. Welcome to the fathers' program," followed with a name tag, a cup of coffee and doughnut, and introductions to the other men. Many programs designate dads to greet both new and veteran members, thus setting a tone of personal regard and acceptance. A tour of the sponsoring facility, an introduction to child care providers, and some printed information about the program, including a calendar of meeting times, all convey to new members that they are indeed welcome — and important.

Meeting Times

Most fathers' programs meet on Saturday mornings. Member and facility availability, and the opportunity to involve children, make this a preferred meeting time. A typical schedule is:

9:00 - 9:30	Arrival, Social Time, and Snacks
9:30 - 10:00	Father/Child Activity
10:00 - 11:00	Open Discussion
11:00 - noon	Speaker or Educational Resource

If a father/child activity is not used, then a 9:30 to noon schedule is often adopted. Again, the preferences of the men are the determining factors.

Some groups favor a weeknight meeting or a combination of Saturday morning and evening times. Although the latter precludes the involvement of children, it also typically reduces employment conflicts. Either discussion only or a combined discussion and speaker is a typical format for evening meetings.

Some groups meet monthly; others meet twice a month or more often. It is recommended that groups meet at least once every three weeks, particularly in the formative stage. Any less than this may make it difficult to build connections among the men, particularly if their attendance is

sporadic. Personal commitment, time considerations, and cost are all factors in this decision.

Father/Child Activities

The majority of groups that meet on Saturday morning encourage fathers to bring their children with special needs. Based on the number of child care providers and the room capacity, some programs encourage fathers to bring all of their children. Aside from giving mothers valuable time off, fathers will also have a chance to learn first-hand about other men's children. This adds depth to the group's discussion and interactions. If children don't attend, fathers should be encouraged to share photographs of their children.

Another incentive for encouraging child involvement is to provide an opportunity for the men to observe the way the other fathers interact with their children. Experience is a powerful teacher. Few men have a clear picture of their child's potential, nor are there necessarily clear developmental guidelines available. Being able to ask questions of other dads can be particularly beneficial.

Photo: Gary Sweet

Kids at the Merrywood Fathers' Network campout

Many researchers note that fathers probably make their "primary contribution" to their children through play (Parke, 1981). A fathers' program is a superb place for fathers to play with their children: "The reciprocal games and activities they enjoy form a foundation for their growing relationship" (Meyer, et al., p. 50). By playing with their fathers, children learn about their own abilities and about how they can affect their environment. Fathers, in turn, learn more about how to appropriately play with their children, and gain insight about their children's ability to communicate their needs.

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Father/child activities will vary according to the size of the group and the ages and abilities of the children. All activities must be developmentally appropriate; nothing can alienate a father more quickly than an activity that is too demanding or too formidable for his child. The resulting embarrassment may prompt a father not to return to the group. Activities that are easy to complete, hands-on, adaptable in outcome, and just plain enjoyable are most effective. Working with early childhood specialists to develop such activities will ensure appropriateness as well as a variety of options to choose from. (See Appendix M for a sampling of activities.) Typical father/child activities include:

- ❑ crafts projects, often built around a theme or holiday (i.e., humor, the environment, Halloween)
- ❑ singing and listening to music
- ❑ simple physical movement activities
- ❑ using materials that stimulate sensory and tactile awareness
- ❑ using adaptive toys, particularly with children whose motor skills are limited

Keep in mind that some fathers may find such activities awkward at first. No father or child should ever feel he cannot perform the activity. Children and dads should be able to complete the projects and find personal success and pleasure in doing so. In choosing activities, one must be sensitive to cultural, ethnic, and religious diversity. For example, avoid Christmas or Easter projects; try theme projects instead.

Another type of father/child activity is visiting local places of interest, such as:

- ❑ children's museums where children and dads can do hands-on activities
- ❑ the aquarium or zoo
- ❑ a pumpkin patch during Halloween season
- ❑ a summer barbecue and picnic with accompanying activities
- ❑ a hike where the trails are accessible and safe

Participation in Special Olympics activities, or other specific ventures designed for children with special needs (fishing, T-ball teams, etc.) is another favorite father/child activity. Before planning one of these outings, make sure that facilities are fully accessible.

Leaders might consider sponsoring a Very Special Arts event as a father/child activity. An educational affiliate of The Kennedy Center for the Performing Arts in Washington, D.C., Very Special Arts coordinates arts programs for people with disabilities. Based on the premise that "the Arts are powerful motivating experiences that provide avenues for delight, pride, accomplishment, learning, and creative education," (Very Special Arts Washington brochure) they have outreach programs in over 15,000 United States communities. Local artists, trained in working with families and children with special needs, present workshops with specific emphasis on music, dance, or drama. Capitalizing on a child's natural love for the arts, the artists help parents learn how to incorporate the arts regularly into a child's life.

When developing father/child activities, group facilitators should fully investigate all available activities for children with special needs. Members will be surprised at how many choices are available, as well as at the willingness of people in the community to help make such activities a success. Taking pictures and making a small scrapbook or picture board is a valuable, enjoyable way to record the outing. Most groups will have dads who enjoy photography and are willing to take on this project.

When a broad age range of children is involved, it may be difficult to provide participatory activities that all will enjoy. For that reason, not all groups have father/child activities. Other programs include these activities only periodically. Few groups initiate father/child activities until the group has gained some cohesiveness and maturity.

Fathers speak, with great pride and enthusiasm, of being able to participate in father/child activities. In the process, the men learn much about communicating, interacting, and playing with their children.

Open Discussion

No component of a fathers' program better embodies the group than the time set aside for sharing and discussion. It is the heart and soul of the program, the reason for the group's existence. It cuts through men's isolation and builds solidarity among group members. Tips for the discussion and sharing component of fathers' support groups include:

- ❑ The discussion should take place in an atmosphere of trust, acceptance, and openness. The men are gathered to listen and respond, not to judge or advise.
- ❑ The discussion should have little or no agenda; the talk must center on the concerns the men bring to the session.
- ❑ Because there are not many places where men can openly communicate and value their emotions, the discussion should often focus on the men's feelings.

It is important to establish clear group norms. No one should be forced to speak, nor should attendance be mandatory. Personal privacy must always be respected. Always remember the character of the group. This is a network of men from diverse backgrounds coming together to share thoughts and concerns about their child and family. It is a place for problems and joys, confusion and clarity.

These discussions often elicit poignant and powerful moments, as well as fresh understanding. Humor, often sardonic, will be in evidence. A common response will be, "I guess I never knew other guys feel the way I do". In such remarks come personal insight and links with other fathers.

> I think men are very proud, and they are afraid to admit they have a hard time handling situations with special needs children. I've learned that I am not the only person with a child with special needs. Talking with other people helps you handle your situation better . . . I've learned to handle things as they come the best I can. [Dan Brinkmeyer]

Know too that some fathers join the group not only because of what they receive, but also for what they can give. They like to know they are contributing something positive to the other men, their families, and the sponsoring agency; it is a reciprocal relationship.

Educational Opportunities

Fathers of children with special needs, in their desire to be productive parents for their children, need information and resources. They want to know how best to help their spouses, how to be effective advocates, and how to collaborate with health and education providers. A fathers' program offers invaluable opportunities to educate and inform.

Through the discussion phase of the meeting, topics will emerge that demand further information and understanding. The group leaders must find resources to address such concerns. Many of these resources will be professionals working in the identified areas of interest (i.e., physicians, teachers, lawyers, counselors). When inviting speakers, some cautions should be noted:

- ❑ The speaker should be given a ***clear overview of the program,*** including the group demographics, special concerns, members' expectations, and desired outcomes. Clear directions to the meeting place should be provided. Many speakers will not need payment for their talk. If an honorarium is available, arrangements for payment should be confirmed.
- ❑ Make sure that the professional has a ***positive attitude*** and experience working in partnership with parents.
- ❑ Ask the speaker in advance to use ***language that is clear and free from jargon*** or unnecessary complexity.
- ❑ Ask the speaker to ***keep prepared remarks brief,*** about 15-20 minutes, so that most of the time will be left for questions about specific situations and concerns. This is when personal learning takes place.
- ❑ Whenever possible, the ***speakers should interact with the men;*** lectures rarely are as interesting or enriching as discussion.
- ❑ Ask the speaker to bring ***printed information to reinforce the presentation.*** Besides allowing a father to take material home to share with his family, this gives him another avenue for learning.

These resources can be provided by the facilitators or in collaboration with the speakers. In some groups this information must also be made available in languages other than English.

Videotapes are another excellent source of information. Make sure the video is professionally produced, the information presented is up-to-date and germane to the fathers' concerns. State and county libraries are an often overlooked source of videos and other materials on disabilities and health concerns. Agencies frequently loan videos, and many can be borrowed free or for a small fee. With some foresight, television programs can be videotaped. For example, most public broadcasting stations run excellent mini-series on children, including children with special needs.

Men often want practical, pragmatic information that can be put to immediate use. In doing a group needs assessment (See Appendix G), make sure that the choices reflect this desire. Popular topics include: effective advocacy; financial matters, including trusts, wills, and guardianships; working with insurance providers; rights of children under the Americans with Disabilities Act; child discipline; integration and inclusion; and specific therapeutic modalities for language development and communication.

Information on interpersonal issues must also be emphasized. These include:

- ❑ effective family communication
- ❑ conflict management
- ❑ sibling and grandparent concerns
- ❑ personal challenges in raising a child with special needs
- ❑ coping with grief and loss

These are formidable but critical subjects. Some fathers' programs invite wives and significant others when such topics are offered. The time allotted for such programs also is significantly increased, often two to three hours. In year end evaluations of local programs, men consistently remark that these were the sessions that made the biggest difference in their lives.

Social Activities

When a man first joins a fathers' program, he is often nervous about what is expected of him. He may wonder: "What happens at meetings? What if I break down and cry; will that be acceptable behavior? Who are the men that attend this program, and will I fit in?" Program-sponsored social events help the members get to know and feel comfortable with each other, reducing some of these worries.

A fathers' program creates opportunities for men to meet other dads and their families, to engage in activities together, to connect interpersonally with each other socially through sporting events, completing projects, and sharing laughter and good times.

Fathers' programs around the country have used social occasions in a variety of ways. Certain social events are for ***men only***. These include:

- ❑ attending a sporting event
- ❑ sponsoring a pizza night, often in conjunction with recruiting new men to the program
- ❑ participating in activities such as bowling, volleyball, or softball games
- ❑ completing a project such as a work day for the sponsoring agency (paint, repair), or the making of adaptive toys to be donated to a child care center
- ❑ sponsoring a summer barbecue combined with outdoor activities

Other social gatherings are for the ***entire family***. These serve to introduce spouses, brothers and sisters, grandparents and friends to each other, and to help them understand what the fathers' program is all about. Potlucks are the most common family event. A variation is to have the men prepare a spaghetti feed or pancake breakfast to which families and other friends are invited. Many groups have summer campouts, overnight events where people share food, exchange ideas, and play together.

A third kind of social event is for ***couples only***. The logistics of these events can be quite complex. Child care and finances are primary concerns, and all planning must take these into account. One program offers "respitality" overnights. Local hotels donate rooms on the weekend to couples who otherwise have little time for themselves. Another program has an annual weekend trip, primarily for entertainment, to a neighboring city with its own fathers' program. An organized event between the two groups, such as a Saturday evening meal at a local restaurant, provides ample opportunities for networking. Families are strengthened when couples have opportunities to be alone. In addition to alleviating stress, this allows time for relationship renewal. Sponsored couples-only events highlight the importance of a strong bond between partners.

Outcomes

Organizing a fathers' support group takes careful listening. The leadership must build a structure based on the members' stated needs rather than the leaders' preconceived notions. Such a program creates an atmosphere where men can question, explore, and learn about their children and their families, and, perhaps most importantly, about themselves.

> I have learned that being in a support group of guys who deal with some of the same family stresses and frustrations that I have — some having been down the same paths I am struggling with — can be of great encouragement. They may not have all the answers, but to know they understand, can laugh, tear up, or get hot about the same things I do, for the same reasons, is very beneficial. [Jim Lamb]

Chapter 6

Evaluation

I'll never forget the evening meeting where we were sitting around eating pizza and one fellow showed up with his son. The boy played and had a wonderful time while we went around the circle and shared about our families and concerns as we usually do. When it got around to the young man's father, and he said, 'I have two slight disabilities; one you have seen, he's over there playing with toys. The other is being a mailman named Cliff.' I thought I was going to die, I laughed so hard. Laughter is such great medicine. I know everybody left that evening feeling better for having been there. [Chris King]

Vital to a fathers' program's success is continuing discussion and feedback from the men themselves about the speakers, the activities, the leadership, and structure — all aspects of the group. (See Appendix N for a sample evaluation form.)

Roadblocks To Success

Comments must be taken seriously and changes made where needed. Many men have noted roadblocks to success; in starting a program, the following barriers should be duly noted.

- ❑ ***Failing to make the program fully father-centered.*** The leadership fails to find out *why* the men attend, *how* they want the program structured, and *what* roles they would like to play in making the program effective. Family-centered programs always build on the expressed needs of those in attendance.
- ❑ ***Failing to recruit from enough sources.*** The result is a group too small to develop an ongoing program. Agencies often err in not collaborating with other organizations. The goal is to reach as many fathers as possible, not just the fathers served by a specific agency. Comfort, shared experience, and expertise

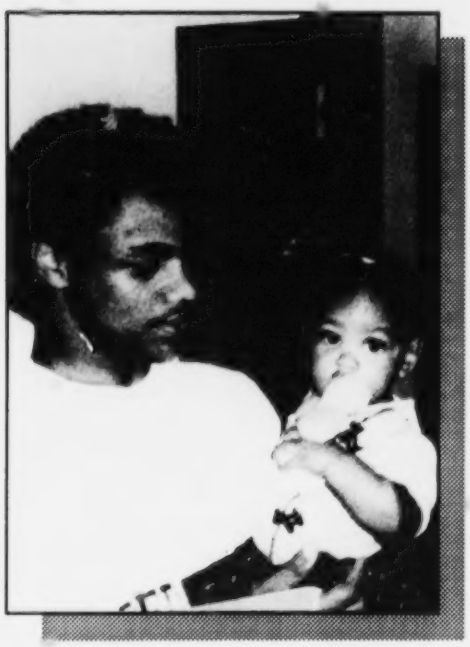

Photo: James May

Kenshabba Brookens with his daughter, De'Lajourea

increase when group members are drawn from varied backgrounds.

- ***Lack of time given for the program to build and grow.*** A fully viable program takes substantial time to achieve, sometimes as long as a year. Some programs will always have small numbers; if that serves the needs of those in the group, then that program will be serving a valuable purpose. However, continual overtures should be made to new dads who might benefit from attending.

- ***Professional leadership is inappropriate — either too detached and uninvolved or overly engaged and controlling.*** The latter describes a "clinical" approach which creates a stilted and formal atmosphere. Few men will find this approach appealing.

- ***Disability or disease focused.*** Fathers of children with special needs have so much in common that a focus on a specific disability often limits rather than helps. There are notable exceptions to this idea, but the emotional concerns men bring to the program generally transcend the child's disability or illness itself.

- ***Viewing the program as an "add on" to the agency's core programs.*** Such perfunctory support ultimately leads to the group's dissolution. The program must be thoroughly integrated into a full menu of services for fathers and their families. Fathers need to be in the clinic and the classroom, learning therapy techniques, attending IEP meetings; and on staff and boards, helping to shape policy and practice.

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- ***Allowing the group to become a place for mostly grievances and complaints.*** A negative approach, although all easy to achieve, ultimately turns most men away from the program and leads to little or no understanding for the men in attendance.
- ***Spending insufficient time on personal sharing and discussion.*** This is the glue that holds the program and the men together, developmentally and interpersonally. Listening to speakers, although they are often of great interest to the men, does not build the bonds that allow the men to know each other and make the program meaningful in their lives.

Criteria for Evaluation

Evaluating a father support program is a difficult process. Numbers may be small, attendance may be erratic, and growth may take many months to occur. What then are the criteria for a successful father support program? How is a program evaluated? The following questions serve as one set of standards:

- Is the leadership organized and skillful, and affirming of the men who attend?
- Is there a strong, consistent core of men attending the program?
- Is the group growing and expanding?
- Do newcomers keep coming back?
- Does the racial, ethnic, cultural, and socioeconomic make up of the group reflect that of the community?
- Do the men willingly involve themselves in the group's activities, whether that means cleaning up or recruiting other fathers?
- Have the men gained increased understanding of how to use the health care and education systems?

Personal Hallmarks for Success

Equally, and perhaps more important are the personal criteria that will be found in the stories told, relationships developed, and observations made. For example, Robert Maxwell values the resource information and believes a support program will add to a man's experience level very quickly. "This saves heartache, time and money. It feels good to be around understanding people, and it makes you stronger seeing the other guys bear up under the strain." Dan Brinkmeyer, in sharing some of the value of a group to him, declares "A fathers' program is very helpful to me. I feel better after meeting and learning what agencies can provide. Membership has given me insight on sources of financial aid."

The following questions can serve as another set of standards for evaluating the more personal aspects of a father support group:

- ❑ Is there an atmosphere of relaxation and ease about the program?
- ❑ Do new fathers feel welcome when they first attend? Do they express excitement about being in the group?
- ❑ Is there an acceptance of the men in attendance — their ideas, their concerns, and beliefs — no matter what background they come from?
- ❑ Do the men exhibit increased support and concern for each other as well as for their families?
- ❑ Is there an open sharing of feelings; are difficult topics and feelings openly discussed, such as sadness, stress, anger, and fear?

Paul Malinowski's comments beautifully capture these personal components:

> I honestly can't say I'm a better parent because of a father support program, although I always get ideas from the other fathers on how to solve problems in parenting. I think, however, that the better one feels about one's self, the better he will be as a father, and a father support program has always made me feel better about myself.

Strong, effective father support programs ultimately answer both sets of questions in the affirmative. As has been noted many times in this

monograph, successful father support programs demand time and patience — indeed, vision. The ultimate evaluation for any support program is encompassed in the question, *Have you changed?* Are you better able to parent your child with special needs? Gary Sweet gives a resounding *Yes!* to such concerns.

> Yes! I am now an activist and deeply involved with rights issues concerning my son. The guys before me broke new ground, and I will continue to advocate for Jacob and, hopefully, break ground for the guys that come after me.

Photo: James May

Jim Narz with his daugher, Angela

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Chapter 7

Final Thoughts

Have I changed? Am I older? Am I wiser? I certainly hope so; isn't that what growing is all about? There must be easier ways to grow in understanding, perseverance, and patience, but I doubt if there are many more effective ways than having children, especially those who have special needs. [Gary Weeks]

Father support programs will not be available in many areas of the country. Not all fathers of children with special needs care to join such a group, nor should they. What other paths are there for men to be increasingly supportive, powerful figures in the lives of their children? How may service providers extend themselves to men in beneficial and rewarding ways? (See Appendix O, *Assessment Sheet for Service Delivery: Fathers of Children with Special Needs.*) What can family members and program leaders do to support fathers and promote the care of their children? The following suggestions are a place to start:

Suggestions For Supporting Male Involvement

- ❑ Service providers and programs need to demonstrate a willingness to involve men, even when it seems they are not interested. The man who gets involved might not be the child's biological father. Men that emotionally touch a child's life in a positive way will also be superb supporters; this includes grandfathers, stepfathers, extended family members, neighbors, and friends.
- ❑ All family members can use help and support at some time. They must learn to ask for help. Lines of communication must always be kept open. Encourage and expect the involvement of all family members, fathers included!
- ❑ Expect a balance in the family where responsibilities *and* tasks are shared. Men *can* advocate for their children, learn how to

feed and use adaptive devices, and understand the intricacies of the laws that protect a child's rights. They must be given a chance to learn these skills.

- ❑ Men need places to share their feelings, especially their fears — what they too often consider "weaknesses". Men who have children with special needs have an overload of feelings, including many they don't recognize or understand. All too often, society and culture have taught men to tune their feelings out. Many hold back for fear of losing control, not being understood, or being seen as weak or a burden. Look beyond the actions and see the messages being sent out. Remember that what you see isn't necessarily what is going on. Fathers must have places to grieve their losses and celebrate their joys; to do otherwise is to live in profound loneliness. Both men *and* women need to be the designated "feelers" in the family.
- ❑ Value a father's offerings as different from a mother's. Promote those differences. Many men want to use their problem-solving skills, whether that be through advocacy, working with health care providers, or building adaptive devices.
- ❑ Fathers make mistakes; that's okay. *All* family members do. Parenting needs to take place without pressure or embarrassment. Many men need to expand their knowledge about children; involvement is expected and necessary. Men should not be allowed to settle into the old, comfortable roles and routines they know best. This is a loss for them and the entire family.
- ❑ Most men do not have models of parenting that are highly nurturing, caretaking or self-disclosing, but they can learn. Men need to talk to their own fathers and heal old wounds, finish old business, and listen to the stories of growing up their fathers have to tell. The writings of Robert Bly, Sam Keen, Kyle Pruett and other authors are invaluable in exploring these concerns.
- ❑ Men working with other dads one-to-one is irreplaceable; such peer support reduces pressure and promotes sharing and openness, and ultimately increases acceptance of the child.

Having a child with special needs puts families in touch with loss; this loss and the accompanying grief is powerful. The love and support of others sustain people through periods of formidable loneliness and isolation. Kathy Parish (1990) remarks that:

> Grieving can be extremely difficult and it takes time. Going through the process leads to a sense of resolution and a chance to embrace life once more. There *is* life after loss. This life is different but so are you (p. 16).

Father support programs significantly contribute to that resolution. The results will be positive change, powerful bonds of friendship, and increased personal understanding and insight.

> I don't remember having much of a heart for individuals with physical or mental handicaps. Then Lisa was born. That, coupled with the connection and experience of seeing other people with special needs through the Fathers' Program, has caused me to realize that they are all people, not problems. They have the feelings I do and so do those who have been called to care for them.
>
> I appreciate so much more fully all the simple blessings of life that I used to take for granted, realizing that for some, those simple things are not simple for them. Small achievements in life for most, I can now appreciate as gigantic victories for others. I am learning to rejoice in those victories, because the perspective I am gaining, slowly but surely, emphasizes just how huge those victories are for certain special people. My heart has grown some to include folks with special needs, but I know, if I were to be completely honest, that there is plenty of room for more growth in understanding, patience, and acceptance. I'm sure, with God's help, it will happen. [Jim Lamb]

Photo: Charles Domingues

Ben Moreno with his daughter, Loida

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SECTION K
Sunday, June 21, 1987
The Seattle Times
Seattle Post-Intelligencer

Scene

Natalie Fobes / Seattle Times
Dana Reed talks about his son, Kyle: "I have a pretty open attitude about my child's disability, but this group is teaching me what difficulties will be ahead."

Special dads, special kids

Raising a child can be difficult; raising a disabled child can be doubly so. For fathers, the burden can be compounded because tradition limits their emotional outlets. Sharing feelings with other fathers can free a man to appreciate the pride and frustration of life with a special child.

Brian Volkert, here with daughter Suzanne, 6, says the group has made him a better father — and husband.

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Group lets fathers share their feelings

by Sherry Stripling
Times staff reporter

In less than a minute, emotions are summarized.

The dads have gathered in this sunlit room in Bellevue as they do every second Saturday morning. Their topic today is how they will handle vacation trips with their kids of special needs.

Some of the fathers say they don't travel on vacations because their disabled child makes it too difficult. Others say it's no problem. One dad mentions that his daughter loves to fly.

"We're thinking of getting her one of those passes and leaving her up there for two weeks," he says.

The rest of the dads laugh. It's a tentative "I-don't-know-if-we-should-really-be-laughing" sound, but the men here all know the feeling of wanting relief from the demands of a disabled child.

In the next instant, the emotion flips.

"Maybe she should be a stew," offers a father.

"Yeah," says the girl's dad, his affirmation wistfully falling, with his glance, to the floor.

This man's little girl never will be a flight attendant because she has mental and physical problems. All the dads here know it. They all remember the feeling when the doctor told them their child had no chance of reaching the potential of other youngsters. All of the dads decided with their wives that they would raise their child at home. And each is here today because he wants to do an exceptional job of it.

Fifteen or 20 years ago, this group might not have worked. The idea of special dads for special children overcomes two stereotypes to place the dads and their kids into common battle against prejudice. Just as their children fight the stereotype of being disabled first and people second, the fathers are often stuck with an image that hobbles their hearts. Traditionally, men are considered providers first and nurturers a distant fourth or fifth. Here, the order is reversed.

It's been nine years since the University of Washington's Experimental Education Unit received a grant to serve the social needs of families with disabled children. Predictions were that support groups for siblings and grandparents likely would succeed, but a separate group for fathers would fail because men would see it as too "touchy-feely."

Ten to 15 men came to the first meeting of the Father's Group. As the group closes its 1986-87 year this weekend with a Father's Day family campout, the local list of dads who have attended one or more meetings stretches to several hundred. The national list adds hundreds more. James May, outreach coordinator for SEFAM (Supporting Extended Family Members), which two years ago moved from the UW to Merrywood School in Bellevue, spreads the seeds of this caring to fathers' groups across the country. May has mobilized men in 17 locations, some as far away as Bangor, Maine.

They come to talk and to listen, because raising a disabled child offers rewards that can be deeply buried by stress, fatigue and drained resources.

"The dads might be socially, economically and emotionally miles apart from one another," says Paul Egly, leader of the Bellevue group, "but when you put them in a room together, they act as if they were blood brothers. The common ground bridges the gap. It's less important what you do for a living than how you're doing for your child."

Egly, who has a daughter and a sister with Down's syndrome, has seen society begin to change its views about people with disabilities. Egly says his parents went against the norm to raise his sister at home. His father openly showed his love, but did not take the active role in daily caretaking more common for this generation of men.

If it still takes courage to show gentleness, then medals of honor should be awarded in the Father's Program. A lanky man in Levi's cradles his developmentally disabled son like a glass football in the crook of his arm. An older man, still attending although his daughter has outgrown the group's early-childhood focus, champions her welfare like a white knight.

"By coming here, I've been better able to judge the type of education Jill is getting," says Bob Mayer of Everett. "I've been better able to get her involved in the right programs."

Egly knows that not every man here will be comfortable talking about feelings, so some distance is allowed.

"We try to make it a non-threatening environment," says Egly. "As men, we don't have the hormones that mothers have. Bonding comes slower for us with babies and infants. This group forces the dads to get involved early, even by just holding the child or changing diapers.

"You are facing a life that is going to be difficult, and the better you bond with that child, the easier it will be."

The meetings run in three stages. First the dads help their kids in play or with crafts. Then the children go down the hall to day care, leaving the fathers time to talk. The third stage — a guest speaker — is periodically skipped so the men can extend their discussion to 90 minutes.

"I have a 3-year-old son who is not handicapped, and I've probably learned some from the other dads about raising him, too," says Dana Reed, who brings his son, Kyle, 1, with him from Monroe every other Saturday morning.

Mothers are invited to hear the guest speakers — who talk about issues relating to finance, health, education and politics — and to attend the social events. But the discussions are strictly for fathers.

May has war stories that reflect how little opportunity men have to share their feelings about life with a disabled child. There's the story of the two men in Maine who worked side by side for five years, never knowing the other had a child with a disability until they met at a group session. There was the group of men in Texas who wouldn't go home after their first meeting. They extended their discussion to the hallway and then to the parking lot, leaning against their pickup trucks as the sun crossed the sky.

Some men come once, listen and don't come back. Egly hopes they are helped simply by knowing there are other men who share common goals. Some men never miss.

Brian Volkert has driven to the semimonthly meetings for 3½ years from his house in Federal Way. The group not only has helped make him a better father, he believes, but it has made him a more understanding husband. Volkert and his wife, Cory, have two young sons and Suzanne, 6, who has developmental disabilities.

When Volkert talks at home, his eyes scan the yard to keep watch on Suzanne. The family has not had a vacation in six years, and he worries that his sons — Paul, 4, and David, 2 — will grow up in their back yard because of restrictions imposed by Suzanne. But he also hopes they will share the enrichment he feels from living with a daughter who struggles to overcome such severe mental limitations.

"Certainly, I have a greater appreciation of life," Volkert says. "Things I took as absolute rights, now, with Suzanne, I see are not rights. I have a greater appreciation that all things are not equal. It has changed my focus on what is important to me."

People without disabled children might be generally sympathetic, Volkert says, but it takes people with the same problems to truly understand. May says that people with disabled kids are more likely to say everything's fine than to go into detail when other parents complain that their children aren't sleeping well or are suffering the "terrible twos."

Volkert agrees. "It's far more difficult to explain a child who is 6 years old and not potty-trained," he says.

Although Volkert occasionally takes Suzanne to work so his co-workers can understand that she is a big part of his life, he relies on the Father's Program for the support his wife says she draws from a female friend who also has a disabled child.

"He talks about it more since he started going to the meetings," says Cory Volkert. It's not easy for the men to admit in a big group that they get angry at their handicapped child or have fought with their wives, she added. But it's important for them to realize that those emotions are part of the process.

Some men never do reveal their feelings, but they keep coming to the group, according to Egly.

"I try to get everybody to join in on the conversation," Egly says. "We make the questions very general. But if people want to get into a discussion on marriage and the stresses on the family, it's by all means open to that. People can be as deep as they want or give a minimal answer."

Studies show that families with a disabled child have higher rates of divorce and child abuse. May says ongoing studies at the UW show the Father's Program decreased stress at home for both husband and wife, improved their communication, lessened fatigue and improved relations with extended family members, such as grandparents.

"The old roles for fathers of providers, protectors and being self-sufficient are good, but they're not enough," May says. "Emotions have to come out somewhere, and too often it's in anger. We would like to validate the role of caretaker and nurturer."

May tells about a man in Philadelphia who brought in "the most fragile little girl I've ever seen." The man felt he had been unable to protect his child from her disabilities and felt guilt because the genetic problems that created them were from his side of the family.

"He told us he goes for whole weeks feeling depressed and doesn't tell his wife because 'I'm supposed to be the strength of the family,'" May says.

Women are more external with their feelings, he adds, and more naturally tuned to information because they're the ones who most often take the child to the doctor or therapist.

"Fathers often get removed from the process," May says. "They get farther and farther behind."

The men in the Father's Program are trying to reverse the process by gaining some control of the future. Fathers of older kids share their successful techniques with fathers of younger ones. The men write letters and visit Olympia pushing legislation to ensure a better life for people with disabilities. They are talking about building a group home to house their children as adults. They swap information on educational opportunities.

"I want to get more involved," said Reed. "I'm a new dad, and I want to find out more about what the guys are doing in their communities. I have a pretty open attitude about my child's disability, but this group is teaching me what difficulties will be ahead so I can look out for them."

Natalie Fobes / Seattle Times

Fathers of disabled children gather twice a month at Merrywood School in Bellevue. The topic of this meeting is summer vacations.

'It's less important what you do for a living than how you're doing for your child.'
Paul Egly
Bellevue group leader

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Appendix B

For Immediate Release:

Sample Press Release

What are the primary concerns a father has when his child has a disabling condition or chronic illness? Where does he turn for personal and family support? Research tells us that fathers often feel isolated, depressed, and left out of services for their children. Relationships may be strained, financial well-being may be jeopardized, and finding appropriate programs for one's child may be overwhelmingly confusing.

The Merrywood School is pleased to announce the formation of a Fathers' Network. The program is for any man who provides primary personal and emotional support for a child with special needs (parent, foster parent, grandparent, close friend). The group will meet every second Saturday morning from 9:30 to noon. There will be a social time, an open discussion, and periodic guest speakers who will share their expertise on such topics as medical research, educational advocacy, coping with family stress, and trusts and guardianships.

There is *no charge* for this program, nor does your child need to attend Merrywood to be eligible. Fathers are encouraged to bring their children with them, as professional child care will be provided. During the year there will be many social activities for the entire family, including picnics, potlucks, field trips to such places as the Children's Museum, and an overnight campout.

The first meeting will take place this coming Saturday, September 7, 9:30 to noon at Merrywood School, 16120 N.E. Eighth Street, Bellevue, Washington. Merrywood is just east of the Crossroads Shopping Center. For more information, call 747-4004 and ask for James May or Paul Blair.

Appendix C

Sample Recruitment Brochure

The Fathers' Network/Merrywood School

A part of Merrywood since 1985, the Fathers' Network is for fathers of children with special needs. You need not be associated with Merrywood to belong. Men are encouraged to attend with their children. Quality professional child care is provided. We meet twice monthly on Saturday mornings from 9:30 to 12:00. Periodic Monday evening meetings are also held. Typical attendance is 10 to 15 fathers. Note the accompanying calendar. The atmosphere is relaxed, upbeat, and fun. Do join us!

Why A Fathers' Program And What Is It?

The Fathers' Network provides important peer support, opportunities for father/child interaction, educators discussing subjects of importance to dads, social occasions for the entire family, and strategies for fathers to be increasingly competent, confident caregivers. Meetings include the following:

- ❑ **Fathers' Discussion** — open conversation on topics of mutual concern to dads, a time to learn and exchange ideas with each other.
- ❑ **Guest Speakers** — experts exploring topics of interest to fathers (i.e., education, medical needs, etc.) — mothers are welcome also.
- ❑ **Father/Child Activities** — developmentally appropriate activities dads and children enjoy together, including periodic field trips to such places as the zoo, Seattle Children's Museum, and the Aquarium.
- ❑ **Social Functions** — potlucks, breakfasts, Summer picnics, a weekend trip to Victoria, for couples, a holiday party, Very Special Arts evenings, sporting events, and our annual Fathers's Day campout in Anacortes. Most social events are for the entire family.

Primarily, this program is an opportunity for fathers to interact with other dads, to share mutual joys and concerns, and to gain increased expertise in parenting a child with special needs.

What Is The Value Of A Fathers' Program?

For more than four years, the University of Washington studied the effects of participation in this program as well as similar programs throughout the country. Findings show that *both parents* benefit from a father's involvement. Parents report less stress, fatigue, and depression, and more satisfaction with the social supports available to them. These benefits appear to endure over time. At present, there are more than 40 such fathers' programs in the United States and Canada.

For More Information:

Call **James May**, Coordinator, or **Paul Blair**, father co-facilitator at The Merrywood School, 747-4004. Transportation is available. There is *no cost* for this program.

Appendix D

Sample Calendar

FATHERS' NETWORK CALENDAR

DATE	TIME	EVENT
September 15	9:30 - Noon	Opening breakfast & discussion
September 29	9:30 - Noon	Speaker: Impact of disabilities on the family
October 13	5:30 - 8:30 pm	Very Special Arts potluck for the entire family
October 27	9:30 - Noon	Speaker: Working with schools
November 12	7:00 - 9:00 pm	Pizza night & discussion
December 1	9:30 - Noon	Speaker: Discipline & behavior management for your child
December 15	10:00 - Noon	Holiday party for the family
January 12	9:30 - Noon	Speaker: Supported employment
February 2	9:30 - Noon	Discussion only, no speaker
February 23	5:30 - 8:30 pm	Family potluck & speaker: Enhancing your child's education at home
March 16	9:30 - noon	Speaker: Sibling Issues
April 8	7:00 - 9:00 pm	Pizza night & speaker: Therapies
April 20	9:00 - 1:00 pm	Merrywood work day
May 3 - 5	Annual couples trip to Victoria. (No children). Stay 1 or 2 nights. Meet with Victoria father's group.	
May 18	5:30 - 8:00 pm	Family Barbecue & speaker: Trust, wills, guardianships
June 1	9:30 - Noon	Final school year meeting: Discussion and evaluation
June 14 - 16	Father's Day Campout at Washington Park — for entire family & friends (Friday evening through Sunday noon)	

Note: All programs are on Saturday mornings unless otherwise noted. Monthly summer activities to be arranged.

Appendix E (letter 1)

Sample Letter

September 29

Dear Dads:

Well, the kids are back in school and the Fathers' Network got off to a grand start last Saturday morning. We welcomed 15 fathers and their children for our annual Fall breakfast. Tons of food was shoveled away, and a good time was had by all. Special thanks to Steve, Bill, and Dave for their trooper work in the kitchen.

Ralph Anderson, a counselor from the Eastside, led us in an excellent discussion of the impact of children with special needs on the family. He spent time on the importance of keeping lines of communication open, developing stress management skills, and working with our extended families. Good stuff. We appreciate his taking the time to be with us.

Our next meeting, October 13, is for the entire family. Every year we invite the people from the Very Special Arts Program to be with us. This year Lora Lue Chiora-Dye will lead us in an evening of African dance and music — guaranteed to get people up and moving around. Lora Lue is well known to this group, as many remember her program from two years ago. Bring your family and friends; all are welcome.

As this is a potluck, please bring enough for eight according to the following alphabetical breakdown: A - I Salads, J - S Main Dish, T - Z Dessert.

We will provide soft drinks, plates, napkins, and utensils.

Child care will be provided for infants. For all others, they will be out singing and dancing the night away. We look forward to your attending. Please R.S.V.P. so we can get an accurate head count for drinks and tables needed.

What:	Very Special Arts Potluck—Music, Dance, and Song
When:	Saturday Evening, October 13, 5:30 p.m. - 8:30 p.m.
Where:	The Merrywood School

See you there.

Cheers,

Paul Blair and James May
Co-Facilitators

Appendix E (letter 2)

Sample Letter

April 11

Dear Dads:

We did it again. We had another successful Monday evening meeting, complete with all the pizza and soft drinks you could consume. And some guys consumed a whole lot! For those who didn't make it, our discussion covered topics ranging from gymnastics (yes, gymnastics) to dealing with the acceptance of our kids with special needs.

As I have said before, but always worth repeating, we are truly proud to be a part of an organization where men can openly discuss their concerns and feelings without the worry of others judging them or preaching to them about how they should act or feel. The care and empathy you men continually show towards each other is extraordinary.

Our next meeting will be April 20th. Our speaker, one of our most requested, will be William Jackson. Bill is an attorney in Seattle, a nationally recognized expert on tax issues, parental rights, trusts, wills, and guardianships for families with children with special needs. This will be an invigorating, thought provoking session. We will finish at noon, and as always, child care will be provided.

Looking ahead, the weekend of May 4th will be our annual couples trip to Victoria. Ten couples have signed up so far. We'll leave Merrywood at 6:45 a.m. (groan!), head to Anacortes and catch the San Juan ferry to Sydney. From there we'll stop at the world famous Butchart Gardens for lunch and a stroll; the flowers should be in full bloom. The rest of the afternoon you'll be at your leisure. That evening, we'll gather with the Victoria Fathers' Group for dinner and fun. Sunday morning we shall indulge in our traditional Sunday brunch. Or sleep in and relax. It's your weekend to do what you want. That afternoon we'll head back home and arrive back at Merrywood no later than 6:00 p.m. There is still room for a few more couples to sign up, but you must do it now.

We hope to see you on the 20th of April. Enclosed is a roster of all the families in this program. Cheers.

What:	William Jackson — Financial Issues for Families of Children with Special Needs
When:	Saturday Morning, April 20, 9:30 a.m. - Noon
Where:	The Merrywood School

Take care,

Paul Blair and James May
Co-Facilitators

Appendix F

Sample Registration Form

Your name _____

Child's mother's name _____

Child's name _____ Age_____ Date of birth _____

Child's disability/chronic illness (optional) _____

Are your child's immunizations up to date? ❑ Yes ❑ No

Names and ages of other children in the family _____

Your address _____

City/State _____ Zip Code _____

Telephone (home) _____ Telephone (work) _____

Emergency contact (name/phone) _____

Family physician (name/phone) _____

Special information about your child (i.e., medical concerns, adaptive devices, medications, allergies, etc.) that will help child care providers. Use the back of this sheet if you need more room for explanation.)

What do you need from this program to make it a positive experience?

Returning this form will guarantee your being sent future notices about this group as well as a program roster. If you do not wish to be on such a roster but still want to receive the twice monthly letters, please check the box below. Thank you.

❑ Please do not publish my name on a group roster. I do, however, wish to be on your regular mailing list regarding upcoming meetings.

— National Fathers' Network

Appendix G

Needs Assessment

Individualizing Your Concerns

The following topics are of general interest to fathers of children with special needs. To make sure we focus on concerns that are uniquely yours, please check three to five topics that are of most interest to you. Add any others that are not already listed.

I have questions/concerns about:	Yes	Comments
1) physicians/therapists		
2) child development		
3) IEP (Individualized Educational Plan)		
IFSP (Individualized Family Service Plan)		
4) speech/hearing impairment		
5) language/communication/speech		
6) nutrition		
7) advocating for my child		
8) family stress		
9) family communication		
10) issues of grief and loss		
11) sexuality/sex education		
12) laws related to children with special needs: P.L. 94-142, P.L. 99-457, ADA		
13) school programs available for my child — current and future		
14) issues of integration/inclusion		
15) finding a program that meets the needs of my family and my child		
16) respite care		
17) money issues: taxes, wills, trusts, guardianships		
18) disciplining my child		
19) self-esteem and my child		
20) special programs: Very Special Arts, Special Olympics, others		
21) extended family concerns (siblings & grandparents, etc.)		

For other topics, use the space below. Thank you for your responses.

— National Fathers' Network

Appendix H

Identifying Feelings

	Happy	Sad	Angry	Confused
1. High	Elated Excited Overjoyed Thrilled Exuberant Ecstatic Out-of-sight Fired-up Delighted	Depressed Disappointed Alone Hurt Left-out Dejected Hopeless Sorrowful Crushed	Furious Enraged Outraged Aggravated Irate Peed-off Seething	Bewildered Trapped Troubled Desperate Spaced-out Lost
2. Medium	Cheerful Up Good Relieved Satisfied Contented	Heart-broken Down Upset Distressed Regretful	Upset Mad Annoyed Frustrated Agitated Hot Disgusted	Disorganized Foggy Misplaced Screwed-around Disoriented Mixed-up
3. Mild	Glad Content Satisfied Pleasant Fine Mellow Pleased	Unhappy Moody Blue Sorry Lost Bad Dissatisfied	Perturbed Uptight Dismayed Put Out Irritated Touchy	Unsure Puzzled Bothered Uncomfortable Undecided Baffled Perplexed
	Afraid	**Weak**	**Strong**	**Guilty**
1. High	Terrified Horrified Scarred Stiff Petrified Fearful Panicky	Helpless Hopeless Beat Overwhelmed Impotent Small Exhausted Drained Numbed	Powerful Aggressive Gung-Ho Potent Super Forceful Proud Determined	Sorrowful Remorseful Ashamed Unworthy Worthless
2. Medium	Scared Frightened Threatened Insecure Uneasy Shocked	Dependent Incapable Lifeless Tired Rundown Lazy Insecure Shy	Energetic Capable Confident Persuasive Sure	Sorry Lowdown Sneaky
3. Mild	Apprehensive Nervous Worried Timid Unsure Anxious	Unsatisfied Under-par Shaky Unsure Soft Lethargic Inadequate	Secure Durable Adequate Able Capable	Embarrassed

—National Fathers' Network

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Appendix I

Fathers' Only Session Questions

Fathers can be each others' best resources. The purpose of this session is to introduce fathers of children with special needs to other fathers. By sharing your experiences and interests, you will help all of the group members develop a deeper understanding of the special joys, concerns, and challenges that are a part of being the father of a child with special needs. We will begin by asking each father in the circle to share with the group your name, where you live, and some information about your son or daughter, such as age, school placement, type of illness/disability, etc. Feel free to ask each other questions and make comments, but pace yourself so everyone gets a turn.

Listed below are some topics you may wish to address when discussing your child:

- ❑ How did you hear about your child's diagnosis? What was your reaction to the diagnosis? Was your response different from your wife's?
- ❑ How has being the father of a child with special needs changed your life? Have your values changed? Have you changed in the ways you parent your children?
- ❑ What is your child's biggest challenge(s) right now?
- ❑ What do you think are the greatest needs of your other children — those who do not have special needs?
- ❑ How do the child's grandparents and other members of your extended family react to your child's illness or disability?
- ❑ When you think about your child's future, what do you see?
- ❑ How do you and your family deal with the stresses of having a child with special needs?
- ❑ Other concerns include:

From *A Handbook for the Fathers Program: How to organize a program for fathers and their handicapped children,* Donald J. Meyer, Patricia F. Vadasy, Rebecca R. Fewell, and Greg C. Schell. Seattle and London: University of Washington Press, 1985.

Appendix J

Elements of Active Listening

Thomas Gordon, in a series of well-known books, among them *Teacher Effectiveness Training* and *Parent Effectiveness Training,* developed a model of active listening. His thesis is that people, while purporting to hear each other, are actually often not listening at all. For many people listening is simply hearing the words of another and then verbally responding. They haven't been trained in the skills — and art — of how to be effective listeners. Though relatively simple in theory, active listening demands discipline, practice, and hard work. When practiced effectively, it is a powerful affirmation of acceptance for another person.

> When a person is able to feel and communicate genuine acceptance of another, he possesses a capacity for being a powerful helping agent.... His acceptance of the other, as he is, is an important factor in fostering a relationship in which the other person can grow, develop, make constructive changes, learn to solve problems, move in the direction of psychological health, become more productive and creative, and actualize his fullest potential. (Gordon, 1971, pp. 30-31)

Dr. Gordon describes a paradox:

> When a person feels that he is truly accepted by another, as he is, then he is freed to move from there and to begin to think about how he wants to change, how he wants to grow, how he can become different, how he might become more of what he is capable of being. (p. 31)

Such acceptance is vital to a fathers' support program. While the men often will be from very different racial, ethnic, cultural, religious and socioeconomic backgrounds, what they all want is to be heard, to be taken seriously, and to be personally valued in the process. Not to receive this acceptance is a form of personal rejection.

Dr. Gordon discusses the cardinal errors of non-listening. These behaviors, often seeming on the surface to be helpful, in reality send the message that a person does not have the ability or capacity to solve personal problems or make positive personal decisions. Advice is viewed as the most helpful — perhaps only — avenue of support. Such ineffective listening produces resistance and resentment, often producing the feeling of being put down. Gordon talks about the roadblocks to effective listening.

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(Continued)

Road blocks to Listening

- ❑ Ordering, Directing, Commanding

  "You should stop worrying about your child so much. You would feel much better if you did."

- ❑ Warning, Admonishing, Threatening

  "With your child's profound disability, your marriage will get really stressed out."

- ❑ Exhorting, Preaching, Moralizing

  "You know far more than health professionals do. Never let them tell you what to do."

- ❑ Advising, Giving Suggestions or Solutions

  "You need to change doctors. He doesn't give you any assistance, and I don't see why you stay with him."

- ❑ Judging, Criticizing, Blaming

  "You are just too easy on your kid. She needs to be pushed harder. Get tougher!"

- ❑ Name-calling, Ridiculing, Shaming

  "You are really a jerk when you act that way. None of the rest of the men in this group treat their families the way you do."

- ❑ Interpreting, Diagnosing, Psychoanalyzing

  "You let your own guilt get in the way of being helpful to your child. I can see it all over your face. You need help."

- ❑ Teaching, Instructing

  "Here's how to talk to your child's special education teacher. It really does work and you'll get better results this way."

- ❑ Praising or agreeing

  "You handle tough situations so well. I wish I had the strength you do."

Appendix J
(Continued)

- ❑ Reassuring, sympathizing, or consoling

  "You and your wife will get through this period of stress. We've all faced it, and we've all done okay."

- ❑ Probing, questioning, or interrogating

  "What is it about your child that makes you so confused and angry?"

- ❑ Distracting, humoring, or diverting

  "Don't worry about it. Go to a movie, take a break, and you'll find the issues won't seem so serious later on."

All of us have used these responses and styles of communication; some have even produced positive results. Yet, such responses most often fail to empower or produce effective problem-solving, in which a person considers for himself what is the most appropriate decision he needs to make. Too often the above responses produce confusion, guilt, frustration, anger, and a sense of not being taken seriously. Effective communication and listening builds rather than limits, supports rather than denies.

"I" Messages

Dr. Gordon talks about positive modes of interaction. He places particular emphasis on the use of "I" messages rather than "you" messages, "You" messages often engender blame, rebellion, and defensiveness. Examples include: "You stop that." "You shouldn't do that." "Don't you ever?" "If you don't stop that, then...." "Why don't you do this?" "You are wrong." "You are acting immaturely." "You want attention." "You should know better than that."

Changing the pronoun from "you" to "I" changes the tone of the conversation. It asks all parties to take responsibility for their messages, their problems, their ideas and feelings. The message is no longer evaluative but instead a statement of fact. "You are a problem" becomes "I am very tired, and it is hard for me to really listen to you today."

Paraphrasing

Also helpful is paraphrasing and restating what one hears another say. This not only helps the listener's understanding, but also lets the speaker know he has been taken seriously. Be careful to avoid formulaic responses such as, "What I hear you

Appendix J
(Continued)

saying is..." Paraphrasing should be natural, not forced, and only done for clarification and understanding.

- ❑ "It sounds as if your frustration with your son's poor schooling really gets in the way of your concentrating at work."
- ❑ "What you would like is more time for yourself; you don't have much privacy or places you can relax."
- ❑ "Am I correct in assuming you are stuck between a rock and a hard place? While you want improved therapies for your child, you don't want to jeopardize your family's financial well-being."

Door Openers

Dr. Gordon talks about "door-openers," invitations for the speaker to say more, to continue talking: "These are responses that do not communicate any of the listener's own ideas or judgments or feelings, yet they invite the [speaker] to share his own ideas, judgments, or feelings." They open the door.

❑ "I see"	❑ " Really"	❑ "Oh"
❑ "You don't say"	❑ "Mm hmmm"	❑ "No fooling"
❑ "How about that"	❑ "You did, huh"	❑ "Interesting"

Other responses are more explicit and ask for increased discussion; they convey the message, "say more":

- ❑ "Tell me more about it."
- ❑ "I'd like to hear more about it."
- ❑ "I'd be interested in your point of view."
- ❑ "Would you like to talk about it?"
- ❑ "Let's hear what you have to say."
- ❑ "Shoot, I'm listening."
- ❑ "This seems like something important to you."

Appendix J
(Continued)

Such responses involve the "sender" and open the door for increased communication and discussion.

Non-Verbal Cues

One should also make sure verbal and non-verbal messages are congruent and consistent. Social scientists make it clear that non-verbal responses are a powerful indicator of what we really feel and believe. Nonverbal messages are sent via gestures, postures, facial expressions, eye contact (or lack of it), and tone of voice. A person on the receiving end of a comment will watch the bodily response and listen to the tone of voice as much as to the words that are spoken.

Primary Attitudes and Personal Competence

Thomas Gordon discusses attitudes necessary for effective active listening. Adapted here for fathers' support groups, they include:

- ❑ Wanting to hear what another father has to say.
- ❑ Genuinely wanting to be helpful to him.
- ❑ Sincerely being able to accept his feelings, however they may differ from one's own.
- ❑ Having a deep feeling of trust in the men's capacity to handle their own feelings and concerns.
- ❑ Appreciating and knowing that emotions are transitory, not permanent. Feelings do change, and despair can turn into optimism, discouragement into hope. One need not be afraid of feelings being expressed; they are not cast in concrete.
- ❑ Viewing others as separate from you, able to have their own lives and identities.

Active, empathic listening takes constant practice. Otherwise it will be just another communication technique, ultimately sounding artificial, empty and insincere. Group leaders should be proficient in this area; modeling this skill helps the men replicate such behavior themselves. All participants need to learn appropriate responses. Not all comments demand active listening; not everyone wants to have an in-depth discussion about his remarks. Active listening is not counseling nor will

Appendix J
(Continued)

it answer all concerns brought to the group. Rather, used skillfully, it will serve to clarify and connect — to assure men they are truly being understood.

The following texts are highly recommended for further understanding of these concepts as well as for principles of group dynamics:

Gordon, Thomas. Parent Effectiveness Training, Peter H. Wyden, Inc.: New York , N.Y., 1971.

Johnson, David W. & Johnson, Frank P. Joining Together: Group Theory and Group Skills, Prentice Hall: Englewood Cliffs, N.J., 1991.

Appendix K

Managing Participant Behavior in Small Groups

Potential Problem Behaviors and Useful Interventions

Emotional Outburst
(crying, being angry or hostile)

Show compassion, empathy. Ask if the man can identify what he is feeling; acknowledge his feelings and then move on. Ask if others are having a similar response. Redirect to another topic. If appropriate, ignore the behavior. Take a break and ask if you can help. Seek to limit the person's potential embarrassment. Schedule a later time to talk one-to-one.

The "Yes But" Response
(interrupting, putting others down)

Acknowledge the man's response, but redirect him back to the central topic or to the person who originated the discussion. Avoid arguing. Refocus on the idea by calling on someone else to respond to it. Use questions to redirect the entire group. Talk to the man at break, and encourage him to share positive experiences in relation to the topic. Ask the group to respond to the man's objections.

The Dominator
(not listening, talking excessively)

Acknowledge and thank the man for his willingness to share ideas, and then call on another participant or say, "now let's hear from others." Set ground rules (clear norms) at the beginning of the session about letting each person have time to share, then politely remind the dominator about this norm. If appropriate, ignore him. Use questions to redirect the group. Use a round robin format; this structure prevents one person from taking over the conversation. Give the person a task that limits this behavior (e.g., taking notes). Talk to the dominator during a break; show appreciation for his participation, but explain that it is important for everyone to have the opportunity to share his ideas.

Appendix K
(Continued)

Side Conversations
(distracting others)

If it is not distracting to the group, ignore it. Ask questions; call on one of the people engaged in the behavior to redirect him back to the group. If the side conversation seems to be due to interest in a topic pertinent to the group, ask them to share their ideas. If appropriate, do a group exercise that removes the man from their side conversation. Stand or sit by the men engaged in the conversation, while you continue to address the entire group.

The Non-Participant

Respect his silence. Know that many individuals take time to develop the trust and the courage to speak out. Establish collaborative expectations and norms about participation at the beginning of a session. If appropriate, call on the man or men by name. Be aware that the perception of the man as uninvolved could be incorrect; many people have different ways of showing their involvement. Watch body language and ask questions (e.g., "I notice you winced (or nodded your head) when he said . . ."). Assign a group task that requires safe, non-threatening input from all participants. Ask the participants if they have anything to add about the specific topic under discussion. Stand or sit by the man to encourage his participation. If no one in the group is participating, ask questions of the group to find out what is going on.

****

Many of these concepts were developed by the Partnership Training Program, National Resource Center for Childhood Rheumatic Diseases, American Juvenile Arthritis Organization. Their permission to share these ideas is appreciated.

Appendix L

Stages of Group Development and Growth

	Interaction Pattern	Process & Focus	Communication
STAGE 1 **Beginning**	Random; leader-centered	Confusion; searching; protective; seeking allies	Guarded; constricted; topic- & situation-centered
STAGE 2 **Norm Development**	Tentative; usually leader-centered or leader-directed	Seeking limits; looking for answers	Security-oriented situation-centered; little self-disclosure
STAGE 3 **Conflict: Differences Accentuated**	Random; centers on one person, or pair, depending on issue	Anxiety; emphasis on differences; possible confrontations	One-way; labeling; increased self-disclosure; often anger & blaming
STAGE 4 **Transition**	Patterns develop; less centered on one leader; expanded	Increased focus on group norms & personal feelings	Increased self-disclosure; more open and less labeling
STAGE 5 **Production**	Focused on task at hand; organized & clear about needs	Cooperation; increased leadership; group is a *group*;	Open, within limits of disclosure; feedback & companionship norms
STAGE 6 **Affection**	Group-centered, but also individual in focus; able to switch back and forth	Relationship norms increase; group flexibility heightened	More self-disclosure & risk taking; positive feedback; an open, constructive working together

Source: Based on a training model in Stanford, G., & Roark, A. (1974). *Human Interaction in Education*. Boston: Allyn and Bacon, Inc.

Appendix M

Sample Father/Child Activities

Craft Projects

Activity # 1: Contact Paper Placemats

Materials: Contact paper, tape, colored tissue paper, construction paper

Preparation: Cut placemat size pieces of contact paper. Tape the contact paper on a table top, wheelchair tray, or other hard surface with the sticky side facing upward.

Activity Description: Place pieces of tissue paper onto the contact paper. Strips of tissue paper can be cut ahead of time or ripped as you go along. When completed, cover with a piece of construction paper.

Adaptations:

- ❑ Place pieces of tissue paper in the child's hands and have her crumple them. Add to the placemat/collage.
- ❑ Place children's hands on the sticky surface of the contact paper for a tactile experience.
- ❑ Place materials on contact paper and have the child pat them down.

Variations:

- ❑ Halloween: Decorate placemats with pumpkin and ghost cutouts.
- ❑ Valentines Day: Decorate with hearts and lace.
- ❑ New years: Decorate with recycled bows and wrapping papers from the holidays.
- ❑ Make a large group contact paper collage by placing a large piece of contact paper on a tabletop, wall, or mirror for children to place materials on.
- ❑ Make a feather or cottonball collage.
- ❑ Make a color collage using a variety of materials of one color.

Appendix M
(Continued)

Activity #2: Sponge Painting

Materials: Sponges, clothespins, tempura paints or other non-toxic paints, construction paper, small trays or plastic lids for paint

Preparation: Cut sponges into small squares and attach to clothespins. Prepare small trays of paint to dip sponges into.

Activity Description: Have children grasp clothespins and dip sponges into paint (or dip for them if necessary). Dab or rub sponges on the paper. Allow children to squeeze sponges and paint with their fingers if desired.

Adaptations:

- ❑ Place a paint-soaked sponge in the child's hands for him to squeeze, allowing the paint to drip onto paper.
- ❑ Place a paint-soaked sponge on paper, and place the child's hand on top of the sponge, allowing her to push it on the paper.

Variations:

- ❑ Tape a large piece of paper on the floor and have the children sit in chairs and paint with their feet.
- ❑ String paint by dipping string into paint and pulling the string across paper.
- ❑ Roller paint using small paint rollers or deodorant bottles.
- ❑ Squirt paint with small squeeze bottles.
- ❑ Paint on a sidewalk or outside wall with water.
- ❑ Make potato prints by cutting designs in a potato, dipping it into the paint and stamping the designs onto paper.

Music Activities

Activity #1: Swaying with Scarves

Materials: Tape recorder or record player, scarves or large pieces of see-through fabric

Activity Description: Give each child a scarf or piece of fabric and have him move while listening to music. Shake the scarves, hide under them, etc.

Appendix M
(Continued)

Adaptations:

- ❑ Sew a band onto the scarf, enabling it to be slipped over the child's wrist.
- ❑ Sway together with one scarf in cooperative fashion.

Variations:

- ❑ Provide one scarf for every two people to pull back and forth in a rowing fashion.
- ❑ Introduce concepts such as up, down, fast, and slow by moving the scarves accordingly.
- ❑ Have children hide under the scarves while the music is on briefly, and pull scarves off when the music stops. Repeat.
- ❑ Dance with scarves.

Activity #2: Elevator Ride

Materials: None

Preparation: Have children lay on the floor or crouch down.

Activity Description: Sing a song about an elevator. Have the children climb floors by raising their bodies up slowly for each floor, until they are in a standing position, then go back down.

Adaptations:

- ❑ Children who are unable to stand can participate by raising a limb or by lifting their heads up and down accordingly.
- ❑ Small children can sit or lie on adults' legs and be raised up and down.
- ❑ Children can also be carried upward and downward in the dads' arms.

Variations:

- ❑ Have children crouch in pairs — facing each other and holding hands — raising up and down together.
- ❑ Introduce concepts of fast and slow by moving at different speeds.
- ❑ Introduce concepts of loud and soft by singing accordingly.

Appendix M
(Continued)

Movement Activities

Activity #1: "Row, Row, Row Your Boat" With Partners

Materials: Boat props if desired

Preparation: None

Activity Description: Sit on the floor facing the child an arms' length apart and grasp hands. Sing the song, "Row, Row Your Boat," while moving in a rowing motion with the child.

Adaptations:

- ❑ Have the children sit on adults' laps and cooperatively move together.
- ❑ Move wheelchairs back and forth in rhythm with the music.

Variations:

- ❑ Have the children row together in pairs.
- ❑ Have the children sit in a large circle holding hands and rowing to the right and left.

Activity #2: Blanket Swinging

Materials: Blanket

Preparation: Two adults need to be present to hold the ends of the blanket.

Activity Description: Place the blanket on the floor. Have the child lay on her back in the middle of the blanket. Have the adults pick up both ends and swing.

Adaptations:

- ❑ For children needing additional support, place a bean bag on the blanket for the child to lay on.
- ❑ Pull the child along the floor while he is laying on the blanket if she is fearful of swinging in the blanket.

Variations:

- ❑ Make a fort with the blanket.
- ❑ Hide under the blanket.

Appendix M
(Continued)

Activity #3: Cardboard Box Play

Materials: Large cardboard boxes

Preparation: None

Activity Description: Have children sit inside boxes. Push or pull them along, pretending the boxes are cars or trains.

Adaptations:

- ❑ For children who are unable to sit inside the boxes, put bean bags or supportive chairs inside the boxes to assist them.

Variations:

- ❑ Cut holes in the boxes for playing peek-a-boo.
- ❑ Make a fort with the boxes for crawling in and hiding in.
- ❑ Toss bean bags into the boxes.
- ❑ Paint the boxes.

Sensory Activities

Activity #1: Shaving Cream Play

Materials: Shaving cream, aprons if desired

Preparation: None

Activity Description: Give each child a small amount of shaving cream on his hands — to feel, squish, rub or pat. Rub the shaving cream on the table, and make designs by moving hands and fingers.

Adaptations:

- ❑ Do shaving cream play with feet while seated in chairs.
- ❑ Spread the shaving cream on a wheelchair tray, highchair tray or similar seating tray.

Variations:

- ❑ Have a car wash using shaving cream, toy cars, toothbrushes and a tub of water for rinsing the cars.

Appendix M
(Continued)

- ❑ Push toy vehicles through the shaving cream.
- ❑ Add food coloring or non-toxic paint to the shaving cream for added interest and exploration.

Activity #2: Water Play Animal Wash

Materials: Plastic tubs, water, plastic animals, sponges or washcloths, soap towels

Preparation: Fill tubs with warm water. Add soap and plastic farm or zoo animals.

Activity Description: Wash the animals with a sponge and dry them with towels. Name the animals and body parts as you carry out the activity.

Adaptations:

- ❑ Place water-soaked sponges in the children's hands, allowing them to squeeze the water out.
- ❑ Place the children's hands in the water, allowing them to explore and splash. Do the same with feet.

Variations:

- ❑ Add extra soap to the water and make bubbles by splashing or by blowing through straws.
- ❑ Wash dolls.
- ❑ Wash toy dishes.
- ❑ Wash plastic vegetables and fruit.
- ❑ Wash toy animals.
- ❑ Experiment with objects that float and sink.

— National Fathers' Network

Appendix N

Evaluation of Fathers' Network

Please take a few minutes to evaluate the following programs according to the following ratings: 5 = excellent; 4 = very good; 3 = good; 2 = fair; and 1 = poor. Rank only those programs you attended or can remember.

_____ A Discussion about the impact of disabilities on the family
_____ Very special Arts potluck (evening program and dinner)
_____ Working with the schools
_____ Discipline and behavior management for your child
_____ Supported employment
_____ Enhancing your child's education at home
_____ Sibling issues and panel
_____ Therapy for your child (physical & occupational)
_____ Trusts, wills and guardianships
_____ Grandparent issues

We have also had three sessions devoted to discussion only; rate these:

_____ Comments:

We had two potlucks, a barbecue, and four Monday evening pizza and discussion times; rate these:

_____ Comments:

Would you like more Monday evening programs next year? Yes _____ No _____
Would you like more father-child activities next year? Yes _____ No _____
How did you find the quality of child care provided? Rate the personnel:

_____ Comments:

Comments regarding the program leadership:

For next year, what would you like more of and less of?

Suggestions for topics, speakers, and activities for next year:

Appendix O

Assessment Sheet for Service Delivery: Fathers of Children with Special Needs

Use the following questions as a means for assessing your agency or organization's effectiveness in providing services for fathers of children with special needs.

Yes	No	Service Delivery — Questions for Active Consideration
		Do you have staff in-service programs about improving the quality of service delivery to fathers/males? Is some of the training provided by fathers themselves?
		Do you incorporate what has been learned from fathers into curriculum and in-service programs for staff and professionals?
		Do you employ male staff members?
		Do you have fathers on agency/organization boards and standing committees?
		Do you involve men/fathers in all aspects of program development, from policy to implementation?
		When family/child intake is being completed, do you make an effort to have the father in attendance?
		At intake, if the father is not in attendance, do you inquire about the father or other important male figures in the child's life? Do you make it clear that the father or a key male figure is important and necessary in the delivery of services to the child and family?
		When a father/male attends a meeting with his wife or significant other, do you direct ideas and questions towards him? Do you lead him to believe his input is valued?
		When you telephone a family at home, do you talk with the father as well as the mother?
		When the mother is the custodial parent, do you also mail all materials regarding the child to the father (if approved and legally appropriate)? Do you give him adequate notice regarding upcoming meetings?

Appendix O
(Continued)

Yes	No	Service Delivery — Questions for Active Consideration
		When scheduling an I.E.P. or I.F.S.P. meeting, do you give the family adequate lead time (at least two weeks) so the father may arrange his work or personal schedule to attend?
		When scheduling an I.E.P. or I.F.S.P. meeting, do you make every effort to have the father in attendance?
		Does your agency/organization schedule the I.E.P./I.F.S.P. meetings at hours conducive to father attendance (i.e., early morning, late afternoon, Saturday mornings)?
		Do you have fathers routinely involved in agency and organization services and programs (therapy, the classroom)?
		Does your agency/organization newsletter and printed material reflect the valuable concerns and roles men play in the lives of their children (i.e., a column written by a father, an article aimed at fathers); do your materials and hallways have pictures of men with children?
		Do you have programs aimed specifically at fathers (i.e., father panels, Pops 'n Tots nights)?
		Do you have a father support program available in the agency or the local area? Do you give men information about the program? Do you ask mothers if you can make a referral of the father to this program?
		Do you have fathers of children with special needs available on a one-to-one support basis for discussion, information, and sharing?
		Do you have a quality resource library available (written, audio, video) so a father may gain necessary information about the chronic illness or disability of his child?

For further reading:

Davis, Phillip B., & May, James E. (1991). Involving fathers in early intervention and family support programs. *Children's Health Care*, *20*(2), 87-92.

— National Fathers' Network

YOUR TURN TO SHARE

You have been reading *Circles of Care and Understanding*.

Does this monograph meet a need? ❑ Yes ❑ No

Is this a high quality document in its:

Content? ❑ Yes ❑ No

Tone and Writing Style? ❑ Yes ❑ No

Layout? ❑ Yes ❑ No

How have you used or will you use this document?

Will you recommend the use of this monograph to others? ❑ Yes ❑ No

Do you need more resources dealing with the topic of fathers of children with special needs? ❑ Yes ❑ No

If so, what kind of resources do you need?

Are you a parent of children with special needs? ❑ Yes ❑ No

Thank you for the time that you have taken to answer our questions. Your reactions are important to the National Center for Family-Centered Care and the National Fathers' Network as we develop further resources.

Please return to:

National Center for Family-Centered Care
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3015

National Center for Family-Centered Care
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
301/654-6549

NFN NATIONAL FATHERS' NETWORK

National Fathers' Network

The National Fathers' Network is a rapidly growing group of men, all of whom have children with special needs. The Fathers' Network is part of the Parent Network, National Center for Family-Centered Care, Association for the Care of Children's Health (ACCH). Goals of the Network include:

- ❑ sharing ideas and concerns
- ❑ developing father support programs
- ❑ networking with each other through a quarterly newsletter, and
- ❑ promoting fathers as important, caring people in their children's and family's lives

At present there are Network members in the United States, Canada and Europe. WE WELCOME YOUR PARTICIPATION. Please write articles for us, suggest topics of interest, and be a part of an increasingly important source of support for men. Our newsletter is published four times a year; there is NO CHARGE for membership. If you know of other men or organizations who would benefit from this publication, please write and give us their names. Your efforts are appreciated.

Please add the following name(s) to the NFN mailing list:

Name _____

Address _____

City _____ State _____ Zip Code _____

Home Phone Number (AC) _____

Return this form to:

National Fathers' Network
The Merrywood School
16120 N.E. Eighth Avenue
Bellevue, Washington 98008
206.747.4004 and 206.282.1334
Attention: James May, Editor

A program of the Association for the Care of Children's Health

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About the Author

James May is Project Director of the National Fathers' Network, a program of The Merrywood School in Bellevue, Washington. A subcontractor to the National Center for Family-Centered Care at ACCH, the National Fathers' Network advocates for fathers of children with special needs through trainings, support program development, curriculum development, and dissemination of a quarterly newsletter. Mr. May, an educator and mental health counselor, with Masters' degrees in counseling and applied behavioral science, has worked with families and young people for 28 years. His wife and daughter are dedicated to and work in the arts. James is very involved in volunteering for the American Juvenile Arthritis Organization (AJAO). He also works with parent/professional teams on the Family and Community Networks Project to develop support networks for families of children affected by HIV, an ACCH program. Children are the great joy of his life.

Photo: Gary Sweet

James May with his good friend Jacob Sweet

ADDENDUM

The National Fathers' Network gratefully acknowledges the work of the S.E.F.A.M. Program, University of Washington Experimental Education Unit, for laying the groundwork for this program to develop and grow. Special thanks to Donald Meyer, Patricia Vadasy, Rebecca Fewell, and Greg Schell for their seminal work in this area; that the program has flourished is testimony to their vision, commitment, and hard work.

Portions of this monograph are based upon material in *A Handbook for The Fathers' Program: How to Organize a Program for Fathers and Their Handicapped Children,* Donald J. Meyer, Patricia F. Vadasy, Rebecca R. Fewell, and Greg C. Schell, Seattle and London: University of Washington Press, 1985.

"Guidelines for Facilitating Fathers Support Groups" (pp. 24-27) are influenced and partially adapted from the work of Bill Cox.

Appendix H ("Identifying Feelings") is adapted from a variety of sources, including *A Handbook for The Fathers' Program: How to Organize a Program for Fathers and Their Handicapped Children,* Donald J. Meyer, Patricia F. Vadasy, Rebecca R. Fewell, and Greg C. Schell, Seattle and London: University of Washington Press, 1985; Parent-to-Parent organizations, counseling texts and books on interpersonal communication.

Appendix I ("Fathers Only Session Questions") is adapted from *A Handbook for The Fathers' Program: How to Organize a Program for Fathers and Their Handicapped Children,* Donald J. Meyer, Patricia F. Vadasy, Rebecca R. Fewell, and Greg C. Schell, Seattle and London: University of Washington Press, 1985.